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Quality of life of caregivers of children and adolescents with speech and language disorders

Qualidade de vida dos cuidadores de crianças e adolescentes com alterações de fala e linguagem

ABSTRACT

Purpose: To investigate the quality of life of caregivers of children and adolescents presenting speech and language disorders from their own perspective. **Methods:** Two groups participated, adding up to 40 subjects. Group 1 was composed by 20 caregivers of 4 to 17 years-old children or adolescents with speech and language disorders, paired by age with the Control Group or 2 that included 20 caregivers of children or adolescents with no speech and language complaints. Data collection was done using: two open questions and the World Health Organization instrument, which was translated and adapted to Portuguese language – the World Health Organization Quality of Life Scale (WHOQOL-BREF). The results were submitted to statistical analysis and the open questions were qualitatively analyzed. **Results:** The language disorders distribution showed: stuttering (35%), non-neurological (35%), and neurological oral language disorders (30%). In the analysis of the WHOQOL-BREF scores, there were quality of life differences regarding the physical (1.1%), psychological (0.5%), and social relationships (1.8%) domains. Group 1 presented the most dissatisfying quality of life. Concerning the open questions, it presented good and reasonable characteristics and Group 2, good and very good. The clinical routine and children were mentioned as factors that hamper self-care in Group 1. **Conclusions:** The lowest score of Group 1 in the WHOQOL-BREF was consistent with the open questions results, showing that aspects such as clinical attendance routine and comprehension difficulties influence caregivers' quality of life. The results corroborate that they should be assisted, since they are a group that deserves healthy actions directed to them.

RESUMO

Objetivo: Investigar a qualidade de vida dos cuidadores de crianças ou adolescentes com alterações de fala e linguagem de acordo com a perspectiva deles. **Métodos:** Participaram dois grupos, totalizando 40 sujeitos. O Grupo 1 foi composto por 20 cuidadores de crianças ou adolescentes com alterações de fala e linguagem entre 4 e 17 anos, pareados por idade com o Grupo Controle ou 2, que incluiu 20 de crianças ou adolescentes sem queixas de fala e linguagem. Para a coleta de dados, foram aplicadas duas questões abertas e um instrumento da Organização Mundial de Saúde, traduzido e adaptado para o português – World Health Organization Quality of Life Scale (WHOQOL) Abreviado. Os resultados de tal instrumento foram submetidos à análise estatística, e as perguntas abertas estavam sendo analisadas qualitativamente. **Resultados:** Na distribuição das mudanças de fala e linguagem, havia: gagueira (35%), alterações de linguagem oral sem (35%) e com causas neurológicas (30%). Na análise dos escores do WHOQOL-abreviado, encontraram-se diferenças da qualidade de vida nos domínios físico (1,1%), psicológico (0,5%) e relações sociais (1,8%). O Grupo 1 apresentou qualidade de vida mais insatisfatória; e nas abertas, boa e razoável. Já o Grupo 2 mostrou ótima e boa. A rotina clínica e os filhos foram mencionados como fatores que dificultam o autocuidado no Grupo 1. **Conclusões:** O menor escore do Grupo 1 no WHOQOL-abreviado foi compatível com achados das questões abertas, mostrando que aspectos como rotina de atendimentos clínicos e dificuldades de compreensão influenciam a qualidade de vida dos cuidadores. Os resultados reafirmam a necessidade de que, além de cuidadores, sejam cuidados, entendendo-os como um grupo digno de ações de saúde direcionadas aos mesmos.

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INTRODUCTION

The quality of life (QoL) of caregivers of children and adolescents with speech and language disorders may have a direct influence on their participation and involvement in the therapeutic practice. A family member who requires special care may also influence the emotional, environmental, and physical aspects of others, especially the main responsible for that child or adolescent⁽¹⁾.

According to the World Health Organization Quality of Life Assessment (WHOQOL Group), QoL is defined as the “individual’s perception of his position in life, in the context of his culture and value systems in which he lives, and in relation to his goals, expectations, standards and concerns”⁽²⁾. In this perspective, QoL covers both basic material needs (food, housing, work, education, health, and leisure) and non-material needs (happiness, freedom, personal and professional satisfaction, education, and social inclusion)⁽³⁾. When considering the scope of the term QoL, it is possible to directly relate it to health.

Because of its large territory and regional differences, Brazil is known for social inequalities that are also reflected in the population health⁽⁴⁾. An important milestone for the development of healthcare in the country was the creation of the Unified Health System (SUS), which was established by the 1988 Constitution and ensured that health was considered a general right and duty of the State. Since then, actions of promotion and health prevention, gained prominence, which previously were not in the focus⁽⁴⁾.

The development of the health sector can be observed in the data presented by the Brazilian Institute of Geography and Statistics (IBGE) in the 2010 Census, which, among other information, included increased life expectancy and reduced infantile mortality⁽⁵⁾. Investment in research and hospital equipment, as well as the State’s duty to ensure health to all, are some of the factors that influenced the reduction of child mortality and survival of children in need of continuous care and specialized rehabilitation services⁽⁶⁾. With increased life expectancy, the number of caregivers responsible for children also increased, thus being necessary actions directed not only to the children but also to their parents.

The health condition of the individual influences his QoL. To investigate this effect, several studies have been conducted, and instruments to assess QoL not only of people with a health problem, but also for their caregivers have been developed and tested^(7,8).

One of the tools developed by the World Health Organization (WHO) to evaluate QoL is the WHOQOL. First, an extended version (WHOQOL-100) with 100 questions was created. From the need for a more concise instrument, an abbreviated version, the WHOQOL-BREF, was devised. The concise version was translated and adapted for the Brazilian Portuguese⁽⁹⁾. The WHOQOL-BREF is one of the instruments used to assess the QoL of caregivers of people with many different conditions, but it is less used in Speech-Language Pathology. The studies often include individuals from the clinical practice, but not their caregivers, as shown in publications on stuttering⁽¹⁰⁾. A literature review focused on caregivers of children

and adolescents, as found in studies on Down syndrome⁽¹¹⁾, autism^(12,13), aphasia⁽¹⁴⁾, and cerebral palsy^(15,16). One of these studies that compared the QoL of parents of autistic children to those with children without this condition showed that the QoL of caregivers of autistic children was most affected with regard to the physical and social relationship domains and that the QoL of those responsible for people who need specialized care may be impaired⁽¹²⁾.

The caregiver is the closest person who spends most of his time with the individual and plays an active role in the speech-language therapy⁽¹⁴⁾. In many situations, it is a family member of the individual who is in need of a special care. In several health areas, QoL has been the target of various studies. However, in the context of Speech-Language Pathology, there are few studies with this purpose. The interest of such investigation arises from the requirement for health attention of caregivers and the creation of new public policies to provide training and support⁽¹⁷⁾.

Information on the new model of health should be present in the training of health professionals. This new model is used in different government proposals in Brazil, such as the Family Health Program (FHP), which focuses not only on the disease, but also on all contexts surrounding the individual, including family⁽¹⁸⁾. In this sense, there is a tendency to value family and all the people involved in the health/disease process, which reiterates the importance of studies like the one proposed here.

One of the concepts based on this new health conceptualization is the Extended Clinic, which provides service that “focus on the individual, disease, family, and on the context, aiming to produce health and increase the autonomy of the individual, the family, and the community. This concept utilizes the integration of the multidisciplinary team, customer assignment and relationship building, development of therapeutic project according to the vulnerability of each case, and the expansion of intervention resources on the health/disease process⁽¹⁹⁾.”

Thus, not only the disease of the individual should be considered but the context of the individual should also be taken into account. To guarantee the health and well-being of everyone involved in the process, national and international health policies — such as those from WHO — recommend and emphasize the importance of comprehensive care of the individual, which also includes the family and caregivers. In this perspective, both the individual and the family, comprehended in their environment, will have a space to be treated.

Considering that there is still little research being conducted focusing on caregivers of individuals with speech and language disorders; the importance of self-care; and their crucial role in the rehabilitation process and social integration of children and adolescents with speech and language, the research on this topic is relevant.

Thus, this study aims to investigate the QoL of caregivers of children and adolescents with speech and language disorders to enhance ways to completely accommodate them in the Speech-Language Pathology clinic.

METHODS

Research design and location

This study is a cross-sectional study conducted in the Speech-Language Pathology clinic at Universidade Estadual de Campinas (UNICAMP). The study was approved under protocol number 379/2010 by the Committee of Ethics in Research of UNICAMP, in accordance with Resolution 196/96 of the National Health Council (CONEP).

Corpus

The study consisted of two groups of caregivers with 40 participants, including 20 participants in each group. Group 1 consisted of caregivers of 20 children and adolescents between the age group 4 years and 17 years, with speech and language disorders, who are treated in a Speech-Language Pathology school clinic. Group 2 included 20 caregivers of children and adolescents without speech and language complaints.

Data collection procedure

Data were collected with the use of WHOQOL-BREF and two open questions: “tell us a little about your QoL” and “the action of the people regarding the speech or language difficulties of your child or adolescent” — the second question applied only to Group 1. Information regarding the general identification of participants (age, income, or occupation) was collected by profile consultation. Open questions, answered in writing by caregivers, were applied before the WHOQOL-BREF questionnaire, to prevent influence on the responses.

The WHOQOL-BREF, in its translated and Brazilian Portuguese adapted version(9), is composed of 26 questions. Of these, two questions are related to the assessment of QoL and the remaining 24 questions covers four domains of physical relationships (pain, energy, sleep, and mobility), psychological relationships (feelings, self-esteem, and concentration), social relationships (personal relationships, social support, and sexual activity), and environment (safety, financial resources, healthcare, home, and transportation). Each question is answered on a scale from one to five points. The values of one and two equals negative aspects of dissatisfaction with the question that was assessed. The score of three reveals an aspect of intermediate satisfaction. The values of four and five correspond to positive satisfaction with the domain being assessed. The application of both the open questions and the WHOQOL-BREF occurred in two ways. First, the caregivers in Group 1 were gathered, mostly in small groups, where they were given instructions to complete the questionnaire, and everyone answered the questions at the same time. The same procedure was applied in Group 2, but the application was carried out individually in some cases.

Data analysis

Written statements by the participants were analyzed qualitatively. The responses were then compared by analyzing the QoL aspects.

After application of the WHOQOL-BRIEF, the calculation of standardized domains of the questionnaire and the average of the four domains (physical, psychological, social relationships, and environment) were calculated. A QoL profile was traced for each group, the data were compared, and the statistical significance was verified with the Breslow Wilcoxon test.

RESULTS

Demographic profile of caregivers and distribution of speech and language disorders of children and adolescents

The profile of the participants was similar in both groups (Table 1).

Table 1. Profile of caregivers regarding age and monthly income.

Variables	Group 1	Group 2
Mean age	40.1 years	36.2 years
Mean monthly income	R\$1616.15	R\$1990.75

The average age in Group 1 was 40.1 years, with ages ranging between 20 years and 66 years. In Group 2, the ages ranged from 19 to 60 years.

The marital status of the caregivers in Group 1 included 65% married, 15% single, 15% divorced, and 5% widowed caregivers. Group 2 included 60% married, 30% single, and 10% divorced caregivers.

The professions in Group 1 included 11 home-based (such as seamstress) caregivers and 9 caregivers who worked outside the home. In Group 2, 18 caregivers worked outside the home and 2 caregivers performed their duties at the residence.

Group 1 consisted of 8 girls and 12 boys, and Group 2 included 10 girls and 10 boys.

The speech and language disorders of children and adolescents in Group 1 included stuttering (35%), oral language without neurological cases (35%), and oral language with neurological causes (30%). The average time of speech and language therapy was two years.

WHOQOL-BREF results

The results of the WHOQOL-BREF (Table 2) showed significant differences in QoL between Group 1 and Group 2 in the physical ($p=1.1$), psychological ($p=0.5$), and social relationship ($p=1.8$) domains, and Group 1 exhibited more unsatisfactory QoL. The environment domain showed a higher ratio of equality between the two groups.

In the QoL analysis of Group 1, the results indicated that caregivers of female children and adolescents had their lives more affected than those compared with the male children and adolescents, especially in the social and psychological domains (Table 3).

Statistical analysis of the QoL comparison between different speech and language disorders (stuttering, and language impairment with and without neurological causes) could not be performed because of the small sample size.

Table 2. Average scores of quality of life domains (WHOQOL-BREF) and between-groups comparison using the Wilcoxon test

Domains	Groups (mean)		Wilcoxon Test
	1 (n=20) %	2 (n=20) %	
Physical	66,43	78,39	1,1*
Psychological	64,17	77,92	0,5**
Social Relations	61,25	77,08	1,8*
Environment	62,34	65,63	37,7

Significant values ($p \leq 0.05$); *significant at the 5% level; **significant at the 1% level.

Table 3. Comparison of quality of life according to the gender of children and adolescents of Group 1 and between-groups comparison using the Wilcoxon test.

Domains	Gender of children and adolescents		Statistical test
	Female	Male	
	(n=8) %	(n=12) %	
Physical	59,37	71,13	6,8
Psychological	54,68	70,48	3,3*
Social Relations	43,75	72,91	0,8**
Environment	57,81	65,36	38,4

Significant values ($p \leq 0.05$); *significant at the 5% level; **significant at the 1% level.

Testimonials from caregivers about their QoL and language of their children

In the open questions, caregivers of children and adolescents from both the groups addressed similar points when asked to talk about their QoL. Aspects related to food, housing, material goods (clothes and transportation), work, social relations, leisure, physical activity, health, family structure, financial aspects, religion, and the absence of vices like drinking and smoking were raised. Such participants associated satisfaction or dissatisfaction in relation to these aspects to characterize their QoL.

In Group 2, in most cases, the caregivers of children and adolescents without language complaints considered their QoL good or excellent, with the focus of the responses, being the caregivers themselves. These related the fact of having a house — owned or rented available, food for family, and health as major items responsible for QoL.

Job was treated as an activity that provides a higher income for the family, but also restricts the time that caregivers spend with their children or adolescents. Many participants reported that periods that are spent together are quality time, even being reported as not much, it was not addressed as being entirely negative as illustrated by the testimony of participant number 34 (mother):

We are always able to have breakfast and dinner together. Our environment is very harmonious. During the evening we talk about our day (everyone talks). I help children with homework. We organize our home, dinner, backpacks, and uniforms and pray before going to bed.

Most caregivers placed the financial condition as a factor that restricts the possibilities for family recreation, which is one of

the reasons why caregivers reported that although they are satisfied with their QoL, it could still be better.

The responses of Group 1 showed that although the themes that emerged were similar to those of the caregivers in Group 2, they were addressed differently, always associating QoL to individual disorders of children and adolescents. For example, for the question “Tell me about your quality of life,” in all responses, the routine of children and adolescents appears as an issue that directly influences the family routine. This is negative response in most cases, because caregivers use the time they would have for themselves to care for the demands of their children. Thus, the difficulties of children and adolescents are affected besides the QoL of their caregivers.

The parents of children and adolescents with speech and language disorders (Group 1) rated their QoL as good and reasonable. They reported that the routine of their children directly interferes with their own routine because the commitments, in addition to school, involve specialized care with other professionals, such as Speech-Language Pathologist, Physical Therapist, Neurologist, Occupational Therapist, Psychologist, and others. It was reported that the commitment to take children or adolescents to these appointments is the main factor in the lack of time to take care of their own needs, as illustrated by the testimony of participant number 3 (mother):

I work a lot! Daughters to school, ballet, Speech-Language Pathologist, Physical Therapy, Dentist, catechesis; I work in the morning at the commerce; all household work related to five people; all administrative and financial work (pay bills etc.); two Saturdays a month I volunteer at the ministry. I am care taker of the pilgrim chapel; I take my mother to the doctor. That is enough, I am tired.

Financial aspects were cited by three participants as impediments to the realization of family activities and also as possible limiting factors for faster development of the child because they had no financial means to provide form or specialized care.

Another item addressed in the responses of Group 1 was the importance of the support provided by the marital partner, family, and friends. On the other hand, in cases which the participants were divorced or did not received satisfactory support from the partner, a constant complaint was the overload brought by care, especially of younger children, as shown by there port of a participant (father):

I have not enough money to do what I like. I have two children, I have to take them to the doctor, Speech-Language Pathologist, Sobrapar, Dentist, Santa Casa and daycare. My life would improve if the mother helped me to take care of him.

The results showed that the topic “children or adolescents,” for whom the participants were responsible for, was constantly brought up in the responses of Group 1. Because of the fact that they require specialized care, unlike those without speech and

language disorders, caregivers need to devote longer periods to accompany their children on these commitments, taking up time that could be dedicated to themselves. Thus, there were complaints of tiredness, lack of time to devote to individual needs, and activity overload — factors that reflect on their QoL.

Regarding the second question asked only to caregivers in Group 1, “Tell me about the reaction of people to the language disorders,” the participants reported difficulty in communicating with the child or adolescent and negative reaction from people who do not know them, besides negative reactions in adolescence, especially of people of the same age. As reported, changes in the reaction of family and acquaintances after speech and language therapy were mentioned; they began to better understand the child or adolescent, which stimulated their potential.

Caregivers of children and adolescents with speech and language difficulties reported problems of their children in communicating with those people, with whom they do not maintain constant contact. This was not only reported with unknown people, but also with their own caregivers, especially with children and adolescents with limited oral language and/or using gestures to communicate.

Regarding the reaction of people who do not know the child or adolescent, differences between the people who know and who do not know their children, was reported by the caregivers. According to statements by the participants, family members and acquaintances seem to understand the situations, who try to understand their speech and gestures. However, caregivers reported that those who do not know their children have greater difficulty understanding their speech, asking to repeat or asking their companions for assistance. The difficulties of children or adolescents were initially identified and, in many situations, the feelings of sadness and compassion transpired in their speech, as illustrated by the testimony of participant number 18 (stepmother). Such caregiver reported that this situation bothered not only the parents but also the child:

When one does not know about the stroke, she is criticized for wearing a bib because she is already a big girl. But when I explain, they feel sorry and I feel that she does not like this situation.

However, as some participants mentioned, with spending more time together, the strategies to improve communication are discovered and the children or adolescents are seen not only experiencing their difficulties, but are also observed for their capabilities.

After the speech and language therapy, for the changes in family and acquaintance reactions, the caregivers of Group 1 reported changes in how the child or adolescent is viewed, for example, not only valuing their “errors” but also by valuing their abilities. Some of them reported that in cases of stuttering, tips as “breath, speak more slowly, do not get nervous” were no longer used, and the words of children/adolescents were encouraged without speech interruptions, as explained by participant number 3 (mother):

At first, my daughter suffered a lot because people even laughed at her lack of fluency. Friends from school mistreated, mocked her. We ourselves did not like her difficulty in expressing herself in the beginning and we used to tell her to breath, to be calm, and to speak slowly. Error. Then we were told to stop with this conduct. That was a mistake; we were just reinforcing her difficulty. Now she is superfluent.

DISCUSSION

Significant differences between both the groups (Group 1 and Group 2) were found in three domains of the WHOQOL-BREF, namely physical, psychological, and social relationships, with lower scores in Group 1, demonstrating lower QoL in the group of caregivers of children and adolescents with speech and language disorders.

In the physical domain, caregivers from Group 1 presented an average of 66.43%, which is considered regular. The most affected aspects were sleep and energy necessary in daily activities. These are similar results to those found in caregivers of children with different conditions, such as cerebral palsy^(15,16) and Down syndrome⁽¹¹⁾.

The findings of the WHOQOL-BREF were consistent with the responses obtained in the open questions, in which caregivers reported overhead in daily activities and lack of time to devote for themselves.

Aspects, such as self-esteem, body image and appearance, negative and positive feelings, memory, and concentration were part of the psychological domain. In the present study, this was the domain of the WHOQOL-BREF in which the difference between the groups was more significant. In a study with 30 parents of children with Down syndrome (in which the WHOQOL-BREF was used to analyze the QoL), the authors also found that the most affected domain for these caregivers was the psychological relationships⁽¹¹⁾. Some aspects that can be associated to this low score are the psychological, financial, and child care burdens, which can generate feelings of uncertainty and anxiety⁽²⁰⁾.

The domain of social relationships (satisfaction with personal relationships, sex life and support of caregivers, friends, and work colleagues) proved to be a negative aspect of QoL in Group 1. Factors, such as the aid of a social support network, identification with a group, acceptance of own appearance, and attributing meaning to their own lives are important to avoid mental overload and stress^(11,21). Taking into account that social relationships were considered prejudiced in caregivers of this study, it is important to be aware of these aspects and highlight the importance of family in the lives of children/adolescents attending the Speech-Language Pathology clinic.

The results of the WHOQOL-BREF, with lower scores in the psychological and physical domains of caregivers of children and adolescents, with speech and language disorders, were similar to some studies that specifically focused on autism. A study that compared the QoL (WHOQOL-BREF) of parents and caregivers of autistic children to parents of children with different

conditions showed that the areas with lower scores in the group of parents of autistic children were the domains of physical and social relations⁽¹²⁾.

It is evident, therefore, that in families of children with developmental difficulties and in which there are interaction and language difficulties, the QoL of the caregivers may be affected. Understanding that QoL influences the lives of children with speech and language disorders makes clear that actions and health care are needed, as SUS establishes complete care of the patient, therefore, including the caregivers⁽⁴⁾.

In studies in which the psychological domain was shown to be affected^(11,22-24), the importance of specialized treatment for parents was highlighted, especially in the domain of psychological relationships — to promote positive attitudes toward the children.

In the current study, the gender of the children proved to be a factor that influences the QoL of their caregivers. The results indicated that caregivers of girls from Group 1 had their lives most affected, especially in the psychological and social relationships domains (Table 3). One hypothesis that could explain this finding lies in the fact that children with more severe problems, especially of neurological causes involving physical and mental limitations, were girls.

“Children” were mentioned in all responses from Group 1, but this was not found in the responses from Group 2. This fact evidences the differences in demand due to the speech and language disorders of children and adolescents who require special care and more dedication of parents. The specialized care routines and activities of the children were constantly addressed and, in some cases, were presented as a justification for the lack of time for leisure and self-care activities by the caregivers that did not involve the participation of their child or adolescent^(22,24). Caregivers of Group 1 cited the children telling how the daily routine influences their personal expectations and QoL. Similar results were found in caregivers of children with diagnoses that may affect speech and language⁽¹¹⁾. With the aim to verify formal and informal social supports received by parents and characterize QoL, the perception of 150 caregivers through WHOQOL-BREF and a specific questionnaire regarding social support was evaluated. Regarding the formal support being received, 70% of children attended at least three professionals—a situation that demonstrated the availability required by the caregiver. During this time, the priority was the child or adolescent, and not the caregiver. In 68% of the cases, parents reported deprivation of leisure and social relationships because of the fact that they have difficulty in having a life that is independent of their children, always thinking of who would care for their children⁽²⁵⁾.

Furthermore, it appears that the condition of the child/adolescent influenced the profession of their caregivers. The occupations of those caregivers with children/adolescents with no language disorders are carried mostly outside the home environment. In the other group, more than 50% of the participants performed their duties at home as housewife and seamstress. This shows the influence of care in different areas of life, including the choice of occupation.

Tiredness and lack of time for themselves were aspects addressed by caregivers of children/adolescents with speech and

language disorders^(11,16), but these were rarely addressed in Group 2. Although lack of time has appeared in some responses from Group 2, the main cause cited was over working and not the fact that they had to accompany the children and adolescents in appointments or other commitments, as observed in Group 1. As for the action of people before difficulties of speech and language, one of the most discussed issues was the complexity of communication with people with whom the child/adolescent had less contact. This is found in several pathologies that can interfere especially in the efficacy of oral language, as in cases of Down syndrome⁽²⁶⁾ and cerebral palsy⁽²⁷⁾. By not knowing the child/adolescent and often not understanding how communication occurs, strangers have difficulty understanding what the child/adolescent wants to say. Given the dialogic characteristic of language⁽²⁸⁾, there may be difficulty in maintaining a dialogue where one party does not understand the other. Thus, the conversation will often not have continuity.

This can also happen with caregivers, especially for children/adolescents, who use gestures to communicate or those with reduced oral language⁽²⁹⁾. Even if it occurs less frequently, it is important to signal the difficulty of communication in the family due to its impact on the daily dynamics and influence on the QoL of residents of the house, who, many times, do not understand the desires and requirements of children/adolescents and may feel powerless in face of such a situation.

The reports of negative reactions, especially among adolescents, can lead to social isolation and longer periods at home and restriction in participation in social activities. Additionally, there may be times when caregivers leave their social commitments to be with their children, thus also deprecating their QoL. Studies on the possible effects of the presence of a disabled child in the family highlight the importance of knowledge on environmental conditions⁽³⁰⁾. The need for the professional, who not only knows the patients, but also the different domains that pervade them, with emphasis on their parents and caregivers, is discussed. Therefore, caregivers want and deserve to be treated with sensitivity by professionals, who serve their children as active partners in the therapeutic process and who also require care⁽¹³⁾.

In the present study, the lowest score in the WHOQOL-BREF was consistent with the responses presented in open questions, where aspects, such as routine health was not always responded in a positive way as the QoL of caregivers. Therefore, the results shows, the need for health actions directed to the caregivers who also need to be seen and considered in their entirety.

CONCLUSIONS

QoL was considered good or excellent by most caregivers of children and adolescents with no speech and language alterations. Caregivers of children and adolescents with speech or language disorders characterized their QoL as good or regular, revealing the different conditions of the two groups.

The lowest score of Group 1 on the WHOQOL-BREF was consistent with the responses on open questions, which exhibited that routine of health care appointments, comprehension

difficulties, and reaction of people to face difficulties of their children and adolescents, are aspects that influence the QoL of caregivers.

Considering the results in the WHOQOL-BREF and the difference on QoL between the groups, it is necessary to reaffirm that caregivers also need care and need to be seen as subjects and not only as guardians of children and adolescents with disorders in some developmental aspect.

Given current national and international health policy — that emphasizes aspects such as humanization, hosting, and proposals as the Extended Clinic and advocate complete attention to the patient, implying the inclusion of family and other caregivers — the findings of this study reinforce the need and importance of a special approach directed to caregivers of children/adolescents at the Speech-Language Pathology clinic. Therefore, this approach will certainly have repercussions on the development and QoL of all social factors involved, then these actors can be children, adolescents, or caregivers.

**ABZ performed the research as a final paper, counseled by RYSC, and both participated in the development of the article.*

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