

Family participation in the care of children with speech sound disorder

Participação familiar no cuidado de crianças com transtorno fonológico

Delta Regina Fernandes¹ , Bernardino Geraldo Alves Souto²

ABSTRACT

Purpose: To investigate the understanding of parents or caregivers of children undergoing speech therapy regarding the importance of family involvement in the therapeutic project. Methods: Through clinical-qualitative study, the thematic content of thirteen interviews with parents or caregivers of children with Speech Sound Disorder (SSD) was analyzed using the references of Humanization of Health Care, Person-Centered Care and Family-Centered Care. Results: Some interviewees considered family involvement to be important and participated actively in care. Others, however, stressed that contextual factors (environmental and personal) hindered their participation in the therapeutic project outside the outpatient setting. Some did not understand the need for family involvement and focused their criticism on assistance. Conclusion: The therapeutic project of children with SSD needs to include caregivers and family in the care plan, as well as the child being treated. In this project, the perceptions of these caregivers and family members related to SSD should be considered and contextualized in their existential and functional contingencies.

Keywords: Public health; Caregivers; Patient-centered care; Speech sound disorder; Qualitative research

RESUMO

Objetivo: Investigar o entendimento de pais ou cuidadores de crianças em tratamento fonoaudiológico sobre a importância do envolvimento familiar no projeto terapêutico. Métodos: Por meio de estudo clínico-qualitativo, analisou-se o conteúdo temático de treze entrevistas com pais ou cuidadores de crianças com transtorno fonológico, mediante os referenciais da Humanização do Cuidado em Saúde, do Cuidado Centrado na Pessoa e do Cuidado Centrado na Família. Resultados: Alguns entrevistados consideravam importante o envolvimento familiar e participavam ativamente do cuidado. Outros, entretanto, ressaltaram que fatores contextuais (ambientais e pessoais) dificultavam sua participação no projeto terapêutico fora do cenário ambulatorial. Houve, também, quem não compreendia a necessidade de envolvimento familiar e concentrava sua crítica na assistência. Conclusão: O projeto terapêutico de crianças com transtorno fonológico precisa contemplar os cuidadores e a família no plano de cuidados, tanto quanto a própria criança em tratamento. Nesse projeto, devem ser consideradas as percepções desses cuidadores e familiares relacionadas ao transtorno, contextualizadas em suas contingências existenciais e funcionais.

Palavras-chave: Saúde pública; Cuidadores; Assistência centrada no paciente; Transtorno fonológico; Pesquisa qualitativa

Study carried out at Programa de Pós-graduação em Gestão da Clínica, Universidade Federal de São Carlos – UFSCar – São Carlos (SP), Brasil.

Authors' contribution: DRF was responsible for the elaboration of the project, collection, analysis, and interpretation of data, bibliographic review, elaboration of the dissertation that originated the article, writing of the text, and standardization of the rules, according to the criteria of the journal; BGAS was the supervisor of the project and of the dissertation that gave rise to the article, participated in the analysis and interpretation of data, in the writing and critical review of the article with an important intellectual contribution, and the final approval of the version for submission/publication.

Funding: None.

Corresponding author: Delta Regina Fernandes. E-mail: deltaregina@yahoo.com.br

Received: September 18, 2020; Accepted: December 29, 2020



¹Programa de Pós-graduação em Gestão da Clínica, Centro de Ciências Biológicas e da Saúde, Universidade Federal de São Carlos – UFSCar – São Carlos (SP), Brasil.

²Departamento de Medicina, Centro de Ciências Biológicas e da Saúde, Universidade Federal de São Carlos – UFSCar – São Carlos (SP), Brasil. **Conflict of interests:** No.

INTRODUCTION

The Brazilian Unified Health System (UHS) incorporated the participation of the speech-language therapist in all levels of care to offer expanded and comprehensive care through a multidisciplinary team^(1,2).

In the core of Speech-Language Therapy in the scope of this comprehensive care, we can highlight that human communication plays an essential role in life with quality and, mainly, for the social, emotional, behavioral, and cognitive development of children. Therefore, communication disorders can impair children's overall development, consequently influencing the child's life and family dynamics which are recognized as important public health issues⁽³⁻⁷⁾.

Among the disorders that impair human communication, speech sound disorder (SSD) is highly prevalent in the child population. Its characteristic is the inappropriate use of contrastive sounds, which may include errors in the production, perception, and mental organization of the production (storage) of speech sounds⁽⁸⁻¹⁰⁾.

Thus, this disorder causes the child's difficulty in learning and discriminating the phonological system of language^(5-7,11,12).

For the adequacy of the deviant phonological system, different intervention models have been proposed such as the so-called phonologically based therapeutic models⁽¹³⁾. However, regardless of the therapeutic approach, we emphasize the importance of the participation of the child's family for comprehensive care and its effectiveness^(5-7,14,15).

Although this understanding leads speech-language therapists to try to include family members in the therapeutic process, we need to think that family participation may depend on how parents or caregivers perceive SSD and the proposed care plan as well as the resources they have available to collaborate^(10,12).

Nevertheless, research involving families of children diagnosed with communication disorders is scarce^(6,15,16).

In one of these researches, a proposal for speech-language therapy for children with language disorder was elaborated through an approach that included the family and the school in the therapeutic process. The findings showed significant development in the behavior of each child, especially for the oral and/or written communication and social circulation within the family and school⁽¹⁵⁾.

In another study, the author developed a follow-up program for parents of children with delayed language development and/or specific language development disorder. Among other aspects, it concluded that the program allowed parents to learn about what activities they could perform in the domestic environment to promote the improvement of their children's language, becoming partners in the intervention process⁽¹⁶⁾.

The perception of the family and the child regarding the impact of the SSD was investigated through the application of structured questionnaires with semi-open-ended questions. Through an objective approach, the authors concluded that parents were aware of the difficulties faced by their children in terms of interpersonal relationships, emotional state, and learning. The children perceived the impacts of the communication disorder and developed feelings of frustration, shyness, and low self-esteem⁽⁶⁾.

Therefore, thinking about contributing through a more subjective and collective approach regarding family involvement in the care provided to children with SSD, this study aimed to

investigate the understanding of a group of parents or caregivers about the importance of family involvement in the care process. The secondary objectives were to understand the perception of these family members about SSD, their expectations from the speech-language therapy, and the way of family organization for the care of the child.

METHODS

After the approval of this study by the Human Research Ethics Committee (HREC) of the Universidade Federal de São Carlos (UFSCar), through Opinion 2,024,706, we interviewed, between July and September 2017, thirteen family members of children undergoing speech-language therapy at the Specialized Rehabilitation Center (SRC) "Dr. Eduardo Lauand". It is a service inserted in the medium complexity of the Municipal Health Network of Araraquara, in the countryside of São Paulo. All participants signed the Informed Consent Form (ICF).

The possible participants of the research were indicated by three speech-language therapists from the child and adolescent sector of the public health service, by filling out a spreadsheet with data of the children diagnosed with SSD (full name, date of birth, day and time of attendance, the start date of the intervention). According to the different professionals, all children and their caregivers received specific guidance on home care for speech-language therapy, according to the therapeutic need of each case.

The inclusion criteria adopted were: to be a parent or caregiver of a child diagnosed with SSD, between 4 to 8 years old, regardless of the number of phonological processes present, the severity of the disorder, and the type of therapeutic approach received. The children had been in care for at least five months to certify that only parents or caregivers of children in the therapeutic stage who regularly lived with the children and who participated in the care process were part of the research.

Parents or caregivers of children with some other speechlanguage disorder potentially influential on the perception of these individuals in specifically phonological care were excluded

One of the authors of this study interviewed participants individually in SRC "Dr. Eduardo Lauand" service rooms, while the children were attended by speech-language therapists at the service. The interviews lasted between 30 and 40 minutes and were recorded for later transcription.

Thus, data was collected through the application of auxiliary instruments in the field (closed questionnaire and semi-directed interview).

The closed questionnaire aimed at surveying the children's sociodemographic characteristics, according to gender, age, education level and people with whom they lived; and their parents' or caregivers' (research participants) regarding the degree of kinship with the child, gender, age, education, occupation, and family income.

The interviews, in turn, were based on a semi-guided script of open questions through a dialogue that allowed the interviewees to speak freely about the topics of interest for the specific objectives.

To stimulate the speech of the participants on the topics intended by the research, the interview started with the following triggering question: "Tell me about your child and his speech-language therapy treatment". Then, issues related to the way of family organization for child care, expectations about the child's

evolution, and, finally, how the interviewee's participation in speech-language therapy treatment was addressed.

The interviews were applied, therefore, according to the clinical-qualitative method, which seeks the interviewee's reflections on his experience with the studied phenomenon⁽¹⁷⁾ and was ended by saturation⁽¹⁸⁾.

The analysis was based on thematic content, through an ideographic survey followed by a nomothetic organization of the findings⁽¹⁹⁾. In practical terms, we collected the ideas contained in the speech of each interviewee, organized into a collective corpus of findings, according to the themes covered in the interviews. Then, these themes were distributed in categories defined by the dialogue between the research objectives and the focuses pointed out by the interviewees to the questions asked to them. Consequently, the interests of the researchers in what they were looking for and the spontaneous manifestations of the interviewees for the topic addressed received equal consideration and treatment.

The interpretation of the findings, in turn, was based on the theoretical reference of the Humanization of Health Care, Person-Centered Care (PCC), and Family-Centered Care (FCC).

About these references, the Humanization of Health Care is founded on the PCC, a care model that can be defined as a collaborative clinical approach, which is based on the expanded perspective of health care, admitting the need for recognition and comprehensive response to the needs of the person's health. In this perspective, it promotes the sharing of power and responsibility between professionals and users of the services, a component that proposes the person's participation in decision-making about their care, and recognizing, thus, their autonomy, the need to make the appropriate choices to their context of life, their experience with their health condition and their potential for effective participation in the entire care process⁽²⁰⁻²²⁾.

The insertion of the family in this context broadens the approach to the scope of what is called FCC, whose main element is the relationship between families and professionals, which must be based on partnership, collaboration, and negotiation. The adoption of assistance based on the principles of this health care model is based on the understanding that the children's development, as well as their well-being and of their entire family, are achieved most effectively when professionals

activate the capacity of family members or caregivers to meet the children's needs through family involvement in planning therapeutic actions and assisting care^(10,14,23-25).

RESULTS

The studied population

Eleven mothers, one father, and one aunt of children undergoing speech-language therapy were interviewed. These family members, between 22 and 46 years old, had different levels of education and work activities.

Chart 1 shows data referring to the interviewees, according to the kinship degree with the child, gender, age, education level, occupation, and family income.

The research participants lived with children diagnosed with SSD. Nine of the children treated were male and 4 were female. All received weekly speech-language therapy intervention and were in the school process appropriate for their age.

Chart 2 shows the data that characterize the children whose parents or caregivers comprised the sample.

Thematic categories

Based on the data analysis, 4 thematic categories were constituted: "Perception of parents or caregivers about SSD"; "Expectations of parents or caregivers about the child with SSD"; "Organization of the family according to the demands of the therapeutic project" and "Perception of parents or caregivers about the importance of their participation in speech-language therapy treatment".

To describe them in the way they emerged in the interviewees' speeches, they will be presented and exemplified with significant excerpts from the interviews, in which children and their families will be identified by fictitious names.

Chart 1. Description of the research participants according to the degree of kinship with the child, gender, age, education level, occupation, and family income - Araraquara 2017

Fictitious names	Degree of kinship with the child	Gender	Age (years old)	Education level	Occupation	Family income
01. Eva	Mother	F	24	Complete high school	Housewife	D
02. Cátia	Mother	F	39	Complete higher education	Businesswoman	D
03. Vera	Mother	F	46	Complete higher education	Educational Agent	С
04. Sandra	Mother	F	30	Complete high school	Housewife	В
05. Regina	Mother	F	38	Complete high school	Educational Agent	В
06. Carla	Mother	F	44	Complete higher education	Housewife	С
07. José	Father	M	38	Complete high school	Security	В
08. Célia	Mother	F	40	Complete high school	Housewife	В
09. Sara	Mother	F	30	Complete high school	Hairdresser	В
10. Irene	Mother	F	38	Complete high school	Receptionist	С
11. Inês	Mother	F	34	Complete high school	Housewife	E
12. Carmen	Mother	F	37	Complete high school	Security	С
13. Joana	Aunt	F	22	Complete high school	Manicure	В

Subtitle: B = one to two minimum wages; C = two to four minimum wages; D = above four minimum wages; E = non-declared income; M = male; F = female

Chart 2. Description of children with phonological disorder according to gender, age, education, and people with whom they lived - Araraquara 2017

Fictitious names	Gender	Age	Educational level	With whom they lived
01. Pedro	M	4 years old and 9 months	Preschooler	Father and mother
02. João	M	5 years old and 4 months	Preschooler	Father, mother, and sister
03. Lorenzo	M	7 years old and 2 months	2º grade	Father, mother, and brother
04. Laura	F	5 years old and 7 months	Preschooler	Father, mother, and two sisters
05. Rafael	M	6 years old and 10 months	1° grade	Mother and brother
06. Marcelo	M	7 years old and 7 months	2º grade	Father, mother, and two sisters
07. Bernardo	M	6 years old and 9 months	1º grade	Father, mother, and brother
08. Matheus	M	7 years old and 3 months	2º grade	Father and mother
09. Alice	F	7 years old and 10 months	2º grade	Mother
10. Nicolas	M	6 years old and 6 months	1° grade	Father, mother and brother
11. Beatriz	F	6 years old and 10 months	1° grade	Father, mother, and brother
12. Henrique	M	6 years old and 7 months	1° grade	Father, mother, and two brothers
13. Lara	F	6 years old and 7 months	1° grade	Mother, aunt, brother, and two cousins

Subtitle: M = male; F = female

Perception of parents or caregivers about SSD

All interviewees identified the children's SSD. In some reports, according to the perception of family members, the change in the phonological aspect of language did not negatively influence other aspects of child development:

[...] he is a normal child, playing, spontaneous, very intelligent [...]. But the speech is poor ... I started to notice this poor speech in him when he was in ... in the pre-school, [...] I saw that he changed a lot [the sounds of speech]. [...] he is an excellent student [...] very smart. He is a very, very captive child, very happy, he has several friends. (Regina, about her son Rafael).

In contrast, other respondents recognized the impact of SSD on children's development:

He speaks everything wrong! [...] There was a time when he refused to talk because he said he couldn't speak properly and he knew that he called attention because of the way he spoke. Then he started to recoil. [...] He wanted to interact and he thought he was not able to interact. [...] I was very afraid of him entering [...] the 1st grade and suffer a lot of harassment. [...] Sometimes I'm in a pharmacy, I'm in a supermarket, he starts talking to me, I see that people look. [...] Imagine in the first grade what that boy is going to go through, right. (Cátia, about her son João).

There could have been so many difficult things in his life... because he could have been ridiculed in early childhood education because he didn't speak well. Then he was there, a boy in the pre-school 5 talking about titi ti tatatá. Not understanding the alphabet. So, this year he would have suffered even more because he would not understand the alphabet. He was not going to start literacy. (Vera, about her son Lorenzo).

Expectations of parents or caregivers about the child with SSD

The interviewees' expectations about the child with SSD referred to the reorganization of the phonological aspect of the

language and involved their perceptions about speech-language therapy, among other aspects.

There were reports of satisfaction with the speech-language therapy intervention and expectations of improvement in the children's communication skills. Besides, some participants expected evolution in other areas of child development, as exemplified in the excerpt below:

And I realize that this improves literacy. So, this is what I expect from the speech-language therapist, that this process that is already happening [...], that he could speak well, be able to express himself well and, thus, not to be shy, not to be recoiled because of his speech. [...] That he let go, that he was not ashamed to speak, he would be able to express himself correctly. (Vera, about her son Lorenzo).

Some participants claimed to have met their expectations, mentioning that the effectiveness of speech-language therapy has positively influenced the children's quality of life. In this regard, a mother made the following comment:

It did very well. And so ... it changed his life, it changed, right? So, I have nothing to complain about. It changed a lot, it was very good for him, for him as much as for me. (Regina, about her son Rafael).

In any case, the participants who perceived the solution to their anxieties because of SSD valued the treatment and recognized its effectiveness, emphasizing the improvement in the child's quality of life and development, as well as family well-being.

From another perspective, a negative aspect for some interviewees was related to the duration of the treatment, considering that the need for recovery was pressured by the relationship environment:

Look, I thought it was going to be faster. [...] I hope she will speak well. The sooner the better because now she is starting to be bullied at school. (Sara, about her daughter Alice).

The interviewees who expressed dissatisfaction with the speech-language therapy intervention projected the respective reasons for the slowness of therapeutic progress. In this sense, the perception of negative impacts on the child's quality of life possibly influenced the expectation for the brief reorganization of the phonological aspect of the language.

Family organization according to the demands of the therapeutic project

Attendance and frequency to the speech therapy sessions were valued among the child care strategies:

I don't let her miss an appointment [speech-language therapy session] because it is very important for her. (Joana, about her niece Lara).

Family members mentioned doing homework tasks as a family attitude towards the care of the child with SSD, probably due to the guidelines given by speech-language therapists during the therapeutic process.

Some interviewees were committed to carrying out homework tasks:

Every Monday she comes with a folder of activities [material provided by the speech-language therapist] for her to study. [...] During the week until Monday again, I'm studying with her. Not to forget, confuse in the day. [...] We sit down, study. We read, repeat. (Inês, about her daughter Beatriz).

However, family members were not always able to guarantee the performance of the homework due to environmental and personal factors. Some of them reported dedicating reduced time to carrying out homework since the environmental (work, little time with the child, care for other children, and the child's permanence in school full time) and personal (lack of readiness and child's cooperation, tiredness and caregiver stress) aspects were barriers to the process of caring for children with SSD.

A 38-year-old woman, educational agent, mother of two children, made the following statement about the performance of the activities requested by the speech-language therapist:

I taught. He spoke. In the short time that I had because it is a rush. [...] There are times when it is difficult because he stays at school all day, he is a full-time student, right? I did [sighed]. There were days when I couldn't [she sighed]. I'm gonna be honest. Some days didn't work. It didn't because it was a rush, the life. So much to do. There were times when he was too lazy and I was already stressed too. I thought so, today it will not work. (Regina, about her son Rafael).

Perception of parents or caregivers about the importance of their participation in speech-language therapy

Some interviewees recognized that the family members were co-responsible for speech-language therapy care and that overcoming the communication disorder would be achieved only with the teamwork of the speech-language therapist and the family, that is, through partnership and collaboration:

I think my participation is important, right. Without eh ... these aids that she [the speech-language therapist] ends up asking us to do, right, outside, because it is the side we live with the most. Coming here is important, but you have to keep it at home too. [...] Once a week and less than an hour [referring to the frequency and time of the therapeutic session], right? So, there is little time even for the child to memorize, absorb. It is more difficult. It is much more

difficult if we are not at home every day. There's no way. [...] And we always have a little time for them, right? (Eva, about her son Pedro).

In other reports, the interviewees said that contextual factors (environmental and personal) limited family involvement in the intervention:

I think I have little participation. [laughs] [...] It would be more eh ... the work would be more effective [speech-language therapy], it would be more successful if I had ... eh ... conditions and time. [...] With two children at that age as you saw, [...] with everything for me to do. I can't! It's just that I have no other person to do it with me. [...] So, it is difficult. Can I try harder? I can! But, for now, I can't do it [laughs]. (Cátia, about her son João).

On the other hand, some parents or caregivers attributed to the need for family participation outside the clinical environment, the reduced number of sessions and emphasized that more weekly sessions were needed to improve the child's speech. In this case, it is assumed that there was a reduced perception of the importance of family participation, seen as a strategy designed only to supply the "limited" supply of the service:

The hard part is that as it is ... like this ... it is by the government; it is only once a week. [...] I just think so. That there should be more days because it would be faster. So that's like she [speech-language therapist] told me. It will be a very ... slow process ... so it will need a lot of help from people at home with him. (Carmen, about her son Henrique).

DISCUSSION

Mothers were the main caregivers of children for speech-language therapy, as observed in other studies^(26,27).

In the present study, in addition to the identification of the SSD, part of the parents or caregivers mentioned the difficulties of the children and the family concerns related to possible unfortunate aggravations of the disorder, such as behavioral maladjustments, emotional impairment, stigmatization, moral harassment, school and social interaction difficulties.

Respondents from other studies similarly described the perceptions of changes in the phonological aspect of language, its possible negative consequences, and the distress of the people who cared for these children^(6,26,28,29).

In this sense, some studies have highlighted school problems and moral harassment as the most frequent changes and those that caused the greatest concern^(6,26).

The different forms of SSD perception, with or without associated difficulties, were related to the individualized character of the experience of caregivers and children and involved its heterogeneous nature in terms of severity and manifestation. Probably, the informants who recognized it in isolation were caregivers of children who had good speech intelligibility, cases in which the contents of their messages were understood by most of the interlocutors. Conversely, the parents or caregivers who identified this communication disorder with associated difficulties lived with children whose oral emissions were barely intelligible or even unintelligible and, consequently, the understanding of the messages was compromised. In such cases, there were certainly negative impacts on other areas of child development.

Regarding the uniqueness of the experience with SSD and the associated difficulties, other authors described it as a unique phenomenon for each child and his family, dependent on the existential elements mobilized^(20,28).

The participants expected that the speech-language therapy intervention would promote the reorganization of the phonological aspect of language and, as a consequence, improve other areas of child development. In reports of exceeding expectations, that is, in cases of improved communication skills, we noticed that the benefit was not restricted to the child, but extended to the family as a whole, especially regarding the meaning of SSD in the relationship environment, impacting the family self-esteem and resulting in a state of satisfaction.

However, in the face of negative feelings from some family members, it is important that the speech-language therapist reinforces the resilience that the family needs to have to reduce the intensity of suffering before the perception of the slowness of the treatment concerning the anxiety of those who care for the child, influenced by the social pressure they feel. This implies the need for family involvement in setting therapy goals to ensure that the treatment objectives address their concerns and expectations.

The elaboration of an intervention plan together with the family members provides a better understanding of the communication disorder and provides information on the therapeutic prognosis, preventing possible negative feelings and behaviors related to the evolution of the phonological system of language and expectations greater than the possibilities^(20,26).

In this study, the organization of family care for children with SSD meant attending treatment sessions and performing activities indicated by the speech-language therapists to be daily carried out.

In other studies, the commitment to taking children to speech-language therapy sessions and performing homework tasks was also incorporated into the perception of care for children diagnosed with communication disorders^(26,28).

Regarding the perception of the importance of family participation, some interviewees understood their role in the therapeutic process and the relevance of working together with family members and the professional. Another study presented similar findings⁽³⁰⁾.

The sharing of responsibilities among the people involved in the care process must take place at all levels of health care, in which family members or caregivers, and professionals must work together, aiming at comprehensive care and its effectiveness^(14,15,23,24).

Despite the perception of the importance of family participation beyond the clinic, it was observed that some caregivers had difficulties in guaranteeing their involvement in the treatment. In certain cases, there was a mismatch between what the parents considered important and what they could daily do with the child to overcome phonological difficulties. Given the above and based on a clinical approach that considers the person in his life context, the speech-language therapist must understand and adapt the child's needs to the family's possibilities, as part of the health care practices. Thus, to facilitate the elaboration of an accessible, acculturated, flexible intervention plan and responsive to the needs of the assisted person and his family members, it should be respected the different conditions, ways of caring, circumstances, and histories that each family and child bring to the therapeutic context. Therefore, we need to identify

what helps family members to overcome their problems and empathetically consider the way they deal with adversity^(12,20,23,24).

In this sense, the person who plays the role of a caregiver needs to take care of himself and be cared for, so that he can manage the child's difficulty and develop more resolute actions for his development⁽³⁰⁾. Also, in the face of the accumulation of commitments on one of its members, a family approach becomes essential to identify the family's internal resources, which can be mobilized to face the problem. Thus, the health professional must identify and support the potentialities of each family member, applying them in the interest of the therapeutic project⁽²⁰⁾.

In turn, the participants with limited perception of the importance of family involvement in child care need to understand their role in the intervention process. This understanding can be clarified through their participation in orientation sessions and the development of therapeutic actions.

Family orientation sessions favor the incorporation of changes in attitudes by family members for the benefit of the children and, therefore, help to determine the roles of those involved in the care^(26,30).

Finally, the joint planning of the therapeutic project enables a collaborative partnership based on the understanding and agreement on the child's needs, mediated by the individuals' information and autonomy, in which their wishes, possibilities and needs are articulated, as well as those of the child⁽²⁰⁾.

As observed, the contribution of this study was to highlight the importance of the understanding that the professional needs to have about the uniqueness of SSD, its meanings and repercussions in the lives of children, caregivers, and family members, proposing a therapeutic project beyond the reorganization of the phonological aspect of language according to conventional protocols. Speech-language therapists need to understand the suffering caused by SSD in children and their families, as well as the possibility of increasing this suffering due to expectations not yet met during treatment. This understanding can make the work of the speech-language therapist more efficient and effective and comfort and relieve the family when facing the SSD, its direct and indirect repercussions, and the respective treatment.

As a limitation of this study, we point out the lack of consideration between the degree of SSD and the different perceptions of parents or caregivers.

Regarding the epistemological scope of this research based on caregivers and family members of children with SSD, studies with a focus on the perception of speech therapists about the care dedicated to children with SSD by such caregivers and family members become interesting. A dialogue between the findings of this study and those suggested is an opportunity to propose strategies for the qualification of understanding between speech-language therapists and families of children with SSD, within the scope of the therapeutic pact.

The expectation is that this qualification favors the structuring of care plans with a broader and more comprehensive approach in the space of longitudinality that characterizes the treatment of children with SSD.

CONCLUSION

The therapeutic project of children with phonological disorders needs to include caregivers and the family in the care plan, as well as the child being treated. In this project, we must consider the perceptions of these caregivers and family members related to the disorder, contextualized in their existential and functional contingencies.

The perception of family members about SSD and its possible negative impacts on children's quality of life probably influenced the demand for speech-language therapy. Some participants identified it without any associated damage. Other interviewees recognized it regarding its different problems, thus, in the environment of meanings of the respective repercussions in the life of the child and the family itself.

Therefore, the expectations of family members when looking for speech therapy treatment were projected in the reorganization of the phonological aspect of language and, as a consequence, in the improvement of other areas of the child's development, which are recognized as impaired by SSD.

Regarding the perception of the relevance of family involvement, some participants did not understand this need and focused their criticism on the assistance offered. Conversely, some considered the involvement of family members important and actively participated in the care process. Others, however, stressed that contextual problems hindered their involvement in the therapeutic project outside the outpatient setting.

In this way, the family members endeavored to guarantee visits to the speech-language therapist according to the agreed schedule and to follow the prescriptions for the home according to their possibilities, the family structure, and the way of organization of each family given the therapeutic needs. Therefore, we need to consider these factors in the structuring of the therapeutic plan proposed by the speech-language therapist.

REFERENCES

- Penteado RZ, Servilha EAM. Fonoaudiologia em saúde pública/ coletiva: compreendendo prevenção e o paradigma da promoção da saúde. Distúrb Comum [Internet]. 2012 Set [citado em 2020 Set 18];16(1):107-16. Disponível em: https://revistas.pucsp.br/index.php/ dic/article/view/11631/8357
- Santos JN, Maciel FJ, Martins VO, Rodrigues ALV, Gonzaga AF, Silva LF. Inserção dos fonoaudiólogos no SUS/MG e sua distribuição no território do estado de Minas Gerais. Rev CEFAC. 2012 Abr;14(2):196-205. http://dx.doi.org/10.1590/S1516-18462011005000088.
- Zanin LE, Albuquerque IMN, Melo DH. Fonoaudiologia e estratégia de saúde da família: o estado da arte. Rev CEFAC. 2015 Out;17(5):1674-88. http://dx.doi.org/10.1590/1982-0216201517513414.
- Longo IA, Tupinelli GG, Hermógenes C, Ferreira LV, Molini-Avejonas DR. Prevalência de alterações fonoaudiológicas na infância na região oeste de São Paulo. CoDAS. 2017;29(6):e20160036. http://dx.doi. org/10.1590/2317-1782/20172016036. PMid:29160334.
- Furlong L, Serry T, Erickson S, Morris ME. Processes and challenges in clinical decision-making for children with speech-sound disorders. Int J Lang Commun Disord. 2018 Nov/Dez;53(6):1124-38. http:// dx.doi.org/10.1111/1460-6984.12426. PMid:30216607.
- Simoni SN, Leidow IC, Britz DL, Moraes DAO, Keske-Soares M. Impacto dos distúrbios dos sons da fala: a percepção da família e da criança. Rev CEFAC. 2019 Jul;21(3):e10718. http://dx.doi. org/10.1590/1982-0216/201921310718.

- Bellon-Harn ML, Morris LR, Manchaiah V, Harn WE. Use of vídeos and digital media in parent-implemented interventions for parents of children with primary speech sound and/or language disorders: a scoping review. J Child Fam Stud. 2020;(Oct):1-13. PMid:33024404.
- Wertzner HF, Francisco DT, Pagan-Neves LO. Fatores causais e aplicação de provas complementares relacionadas à gravidade no transtorno fonológico. Rev Soc Bras Fonoaudiol. 2012;17(3):299-303. http://dx.doi.org/10.1590/S1516-80342012000300011.
- Namasivayam AK, Pukonen M, Goshulak D, Yu VY, Kadis DS, Kroll R, et al. Relationship between speech motor control and speech intelligibility in children with speech sound disorders. J Commun Disord. 2013 Maio;46(3):264-80. http://dx.doi.org/10.1016/j. jcomdis.2013.02.003. PMid:23628222.
- Watts Pappas N, McAllister L, McLeod S. Parental beliefs and experiences regarding involvement in intervention for their child with speech sound disorder. Child Lang Teach Ther. 2016 Jun;32(2):223-39. http://dx.doi.org/10.1177/0265659015615925.
- Dodd B. Differential diagnosis of pediatric speech sound disorder. Curr Dev Disord Rep. 2014 Set;1(3):189-96. http://dx.doi.org/10.1007/s40474-014-0017-3.
- 12. Sugden E, Baker E, Munro N, Williams AL. Involvement of parents in intervention for childhood speech sound disorders: a review of the evidence. Int J Lang Commun Disord. 2016 Nov/Dez;51(6):597-625. http://dx.doi.org/10.1111/1460-6984.12247. PMid:27017993.
- Gubiani MB, Keske-Soares M. Evolução fonológica de crianças com desvio fonológico submetidas a diferentes abordagens terapêuticas. Rev CEFAC. 2014 Abr;16(2):663-71. http://dx.doi.org/10.1590/ S1516-18462012005000071.
- Pinto JP, Ribeiro CA, Pettengill MM, Balieiro MMFG. Cuidado centrado na família e sua aplicação na enfermagem pediátrica. Rev Bras Enferm. 2010 Fev;63(1):132-5. http://dx.doi.org/10.1590/S0034-71672010000100022. PMid:20339768.
- 15. Gertel MCR. Família e escola: interfaces do atendimento fonoaudiológico de crianças com transtorno de linguagem [tese]. São Paulo: Pontificia Universidade Católica de São Paulo; 2013.
- Gonçalves BRL. Programa de acompanhamento a pais na intervenção fonoaudiológica em linguagem infantil [dissertação]. Bauru: Faculdade de Odontologia de Bauru, Universidade de São Paulo; 2012. http:// dx.doi.org/10.11606/D.25.2012.tde-01112012-215711.
- 17. Turato ER. Tratado da metodologia da pesquisa clínico-qualitativa: construção teórico-epistemológica, discussão comparada e aplicação nas áreas da saúde e humanas. 6. ed. Petrópolis: Vozes, 2013.
- Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. Cad Saude Publica. 2011 Fev;27(2):388-94. http://dx.doi.org/10.1590/S0102-311X2011000200020. PMid:21359475.
- Garnica AVM. Algumas notas sobre pesquisa qualitativa e fenomenologia. Interface. 1997 Ago;1(1):109-22. http://dx.doi.org/10.1590/S1414-32831997000200008.
- Lopes JMC. Consulta e abordagem centrada na pessoa. In: Gusso G, Lopes JMC, editores. Tratado de medicina de família e comunidade: princípios, formação e prática. Porto Alegre: Artmed; 2012. p. 113-23.
- Agreli HF, Peduzzi M, Silva MC. Atenção centrada no paciente na prática interprofissional colaborativa. Interface. 2016 Dez;20(59):905-16. http://dx.doi.org/10.1590/1807-57622015.0511.
- Vaz DV, Jubilini LG, Queiroz LC. Prática centrada no cliente na reabilitação: definição, instrumentos e desafios. Rev Ter Ocup

- Univ. 2017;28(1):122-7. http://dx.doi.org/10.11606/issn.2238-6149. v28i1p122-127.
- 23. Johnson BH. Family-centered care: four decades of progress. Fam Syst Health. 2000;18(2):137-56. http://dx.doi.org/10.1037/h0091843.
- Jolley J, Shields L. The evolution of family-centered care. J Pediatr Nurs. 2009 Abr;24(2):164-70. http://dx.doi.org/10.1016/j.pedn.2008.03.010. PMid:19268238.
- McKean K, Phillips B, Thompson A. A family-centred model of care in paediatric speech-language pathology. Int J Speech Lang Pathol. 2012 Jun;14(3):235-46. http://dx.doi.org/10.3109/17549507.2011.6 04792. PMid:21936758.
- 26. Melo RM, Backes FT, Mota HB. Percepções de pais/responsáveis de crianças com desvio fonológico acerca do desvio fonológico e da terapia fonoaudiológica. Rev CEFAC. 2015 Dez;17(6):1802-13. http://dx.doi.org/10.1590/1982-0216201517621314.

- Souza DMB, Lopes SMB. Percepção da família em relação à atuação fonoaudiológica em um ambulatório. Rev CEFAC. 2015 Fev;17(1):80-7. http://dx.doi.org/10.1590/1982-0216201515413.
- McCormack J, McAllister L, McLeod S, Harrison L. Knowing, having, doing: the battles of childhood speech impairment. Child Lang Teach Ther. 2012;28(2):141-57. http://dx.doi.org/10.1177/0265659011417313.
- Ostroschi DT, Zanolli ML, Chun RYS. Percepção de familiares de crianças e adolescentes com alteração de linguagem utilizando a Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF-CJ). CoDAS. 2017;29(3):e20160096. http://dx.doi. org/10.1590/2317-1782/20172016096. PMid:28538828.
- Santos JLFD, Montilha RCI. Grupo de familiares de indivíduos com alteração de linguagem: o processo de elaboração e aplicação das atividades terapêuticas. Rev CEFAC. 2016 Fev;18(1):184-97. http:// dx.doi.org/10.1590/1982-021620161815115.