

Original articles

Speech-language-hearing therapy and clinical listening in a mental health team: perception of parents of children with autism spectrum disorder

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ABSTRACT

Purpose: to analyze the effects of clinical listening in the discourse of parents of children with autism about the speech-language-hearing work in the team of a Children and Youth Psychosocial Attention Center (Centro de Atenção Psicossocial Infanto-Juvenil).

Methods: a descriptive case study research with nine parents of children with autism.

Results: the parents recognize, in the therapeutic experience with the speech-language-hearing therapist, changes in the quality of communication and relationship with their children, becoming more linguistically open and interesting figures to their children, because they understand the communication dynamics and feel ready to develop it. The parents incorporated the idea that it is through a shared playing that their children develop both subjectively and cognitively. They realize that the change and interaction with and between their children, as proposed by the speech-language-hearing therapy, generate care and enlarge the social repertoire of communication.

Conclusion: speech-language-hearing therapy was considered as belonging and fundamental to the field of mental health in the work with children with autism, which reinforces the listening offered to the parents by the team.

Keywords: Mental Health Services; Humanization of Assistance; Autistic Disorder; Speech, Language and Hearing Sciences

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INTRODUCTION

In the perspective of Brazilian mental health policies, the autism spectrum disorder (ASD) is a condition with very early beginning, so much so that it is also included in the category of development disorders. This expression designates a situation of qualitative alterations in social interaction, cognitive processes, behavior, communication and language, starting in the very early childhood.

According to propositions from the Rede de Atenção Psicossocial – RAPS (Psychosocial Attention Network), more specifically to the “Caregiving guidelines to the people with autism spectrum disorder and their relatives”, the mental disorders are defined as:

(...) alterations of the subjective experience and behavior which are manifested independently of subjacent causes, be them either biological, psychological or social. (...) they are descriptive categories, and not explanatory or etiologic – for such, the term “disorder” is adopted, instead of “disease”, since this last term presupposes known biological etiologies or physical pathologies, which is not the case in the majority of the mental disorders.¹

The history and the experience presented by the child with ASD and their relatives are primordial for the diagnosis and the construction of therapeutic proposals aligned with the needs of each child. The multiplicity of etiologic factors without consensus and the diversity of clinical characteristics of ASD summon the mental health team to the construction of evaluation and intervention spaces increasingly interdisciplinary, in the logic of the enlarged clinic, by means of which the acquired knowledge from the professional centers are placed together, in order to, along with other purposes, create a clinical listening unique to the field of mental health.

The approximation between speech-language-hearing sciences and mental health will be approached here based on the concepts of “core area” and “field” proposed by Campos²; the first refers to “the identity of an area of knowledge and professional practice; and the field, a space with imprecise boundaries where each discipline and profession would seek support in each other to accomplish their theoretical and practical tasks”.

RAPS’ intervention proposal at the Centros de Atenção Psicossocial Infanto-juvenil – CAPSij (Children and Youth Psychosocial Attention Centers) for the children with ASD and their families is based on the

wholesomeness of the caregiving, which supposes, among other things, a user-centered care process, the acknowledgement that they are persons with rights, ensuring that the psychosocial attention be based on social inclusion initiatives, breaking up with long-term internment practices. It is important to mention that the terminology Children and Youth Psychosocial Attention Center was chosen (instead of only Children) because it is, indeed, a service aimed at attending both the children and the youth population. Furthermore, such designation is foreseen in the Regulatory Law no. 854 of August 22, 2012, from the Ministry of Health.

At the CAPSij where the research was conducted, most of the cases attended are of ASD (about 42%, according to a survey from the unit’s management), and it seems that the high incidence of this type of disorder is not only a Brazilian tendency. A recent epidemiologic study, conducted in the United States with children from three to 17 years old, pointed to an estimate of pondered prevalence of ASD of 1:40 children³.

In Brazil, the epidemiologic data on children with ASD are still incipient⁴. Nevertheless, a study on the mapping of attention services for children with ASD identified 650 units offering assistance to this population, of which 431 institutions, the majority, is located in the Southeast Region of the country. The CAPSij constitute (30.9%) of the total sample of the study⁵. This means that there are these many services because there is a considerable demand of ASD cases coming to the Brazilian health services.

Regarding the nosological profile of the medical care given at the CAPSij, research indicated that 208 CAPSij were registered at the CNES (Portuguese for Health Establishments National Register), distributed along 23 of the 27 Brazilian federative units; and in the medical care given, predominated the cases of behavior disorders (29.7%), development disorders (23.6%) and intellectual disability (12.5%)⁶. However, there were not found studies showing specifically how these children and their families are perceived and interpreted by the health professionals, despite these factors being relevant to the development of unique therapeutic projects and to the organization of the care offered by the health teams at the CAPSij.

In the case of the CAPSij here researched, it is important to say that it counts with a structured routine of care offered to this population and their families. The care technologies offered are thought over and articulated based on team evaluations, discussions and clinical practice. The cited care routines are

sustained on the integration of various perspectives: Psychoanalytic-oriented clinical listening; sensorial integration strategies; supplementary/alternative communication strategies for the patients with relevant communication alterations; medicated medical treatment; and, use of behavioral- or interactionist-inspired social and cognitive rehabilitation procedures.

This direction of the care process, as mentioned, agrees with the proposal from SUS (Portuguese for the Brazil's publicly funded health care system) for people with ASD, in which it is suggested that the treatment be integrated with the social and subjective dimensions, by means of developing strategies to potentialize their insertion into social life and enable them to such end – thus, stimulating autonomy and independence¹. Taking on such perspective corresponds to recognizing the person with ASD as a social-historical individual capable of learning and of social inclusion and living.

Hence, it is established that there should not exist a single approach to be privileged in the treatment offered by the CAPSij, nor therapeutic projects closed to the possibilities of change and to the reorientations in attending the demands of children with ASD. This recalls that these children need not only the psychosocial care offered by the CAPSij, but also, for instance, the pediatrics in basic care, pediatric dentistry in specialized care and, of course, high-complexity attention in some cases or in certain moments.

Such considerations are in line with the recommendation that the construction of the Unique Therapeutic Project (UTP) for children with ASD be thought with the various approaches available to the SUS services in mind.

It is important to emphasize that the UTP is a therapeutic plan whose objectives, components and care modalities (individual/group) are built upon each user's singularities, with the caregivers'/relatives' direct participation whenever necessary. The UTP works dynamically, being transformed as the child with ASD develops and responds to the treatment. At the CAPSij, usually two professionals taken on the role of reference-professionals for each case, being responsible as well for monitoring and reassessing the practices aimed at the patients' social insertion and living.

Lauridsen-Ribeiro and Tanaka⁷ suggest that “children and adolescents are developing individuals, and the different stages of this development influence their vulnerability to mental health problems, the way these manifest and the best way to treat them”. This statement corroborates the adoption of dynamic and

unique therapeutic projects for the people with ASD, which requires therapeutic practices capable of articulating different disciplinary knowledges to manage the many variables implied in the development processes of these children and adolescents.

It is important to highlight that the CAPSij have their own institutional design, developed from the peculiarities of their territory and circumscribed in the institutional therapeutic project⁸. Nonetheless, at least one dimension seems to be common to all of them: the clinical listening is the thread of the mental health care, insofar as it is a condition for the possibility of the manifest content (symptoms and complaints) to transit to the latent contents or clinical demands of the cases, which have to do with the means of producing, maintaining or intensifying, signifying, elaborating and dealing with the issues and the suffering on the part of the patients and their relatives.

In other words, it is due to the clinical listening that the CAPSij constitute the sustaining pillars of an enlarged and shared clinic. Listening to the users is characterized as the starting point and the condition for sustaining the work and the understanding of the intra- and intersubjective psychic conditions.

The ways of operating the team care at the CAPSij interfere directly with the clinical practice of all the professionals. To that extent, studies on care practices that include ways of perceiving and interpreting the children and their families may be useful to systematize theoretical, methodological and procedural knowledges of the handling of the ASD, aiding the work of the health teams. It is exactly at this point that this study is situated and justified, specifically at the interface between speech-language-hearing and mental health.

It is to that extent that the goal here is to identify the perception parents of children with ASD have of the work of the speech-language-hearing therapy – its contributions and functions – within the multiprofessional team of the CAPSij, seeking to observe the effects of the clinical listening on the understanding and on the parental discourse about the work they are offered.

METHODS

The research was approved by the Research Ethics Committee of the Pontifícia Universidade Católica de São Paulo (PUC-SP) and of the Municipal Department of Health of the Municipality of Guarulhos-SP, Brazil, with evaluation report number 2.069.413, registered at the Plataforma Brasil CAAE: 55931716.4.0000.5482.

This research is descriptive, designed as a case study with participative and dialogical approach with parents of children with ASD at a CAPSij.

The participative approach in research furnishes the means for the researchers to investigate collective social representations and orientations, through a relation of reciprocity between peers (researchers and participants), with the purpose of identifying and/or understanding social phenomena or epiphenomena, answering questions and building possible strategic routing for the problems studied. It is in this sense that this methodological approach was implanted in this study, being conducted by means of the focus group technique: the possibility of getting in touch with a local situation and, along with those who live in it, build answers to the research questions.

The inclusion criterion was of parents of children with active registry and that were from 2014 until when data was collected for the research (September 2017) undergoing speech-language-hearing care in the individual and group modalities. It was sought to ensure that some parents with longer institutional experience (at least three years) at the CAPSij be present, enabling that, in the group of parents, there would be knowledge of the characteristics and routines of the service and multiprofessional teamwork.

On the other hand, the exclusion criteria were of parents of children who left the institution in the period in question, or cases of institutional admission under the State guardianship, as the possibility of contact would be limited or hindered due to their participation at the CAPSij being discontinued or to legal injunctions. The professionals of the CAPSij team selected 25 parents of children. These were contacted by telephone, 12 of which agreed to participate in the research, though only nine parents actually participated in both focus group meetings.

It is important to emphasize that all the parents who participated in the study is characterized by belonging to low-income popular layers of the society. Of the nine participants, eight were mothers and only one was a father of children with ASD: participant 1 – mother of a 6-year-old boy; participant 2 – mother of siblings diagnosed with ASD, a 7-year-old boy and a 10-year-old girl; participant 3 – mother of a 6-year-old boy; participant 4 – father of a 6-year-old boy; participant 5 – mother of a 7-year-old boy; participant 6 – mother of a 4-year-old boy; participant 7 – mother of a 4-year-old boy; participant 8 – mother of a 10-year-old boy; and, participant 9 – mother of a 2-year-old girl.

Since the goal of the study was to identify the effects of the clinical listening on the understanding and on the parental discourse about the work offered them, it was not considered necessary to present a thorough characterization of the subjects.

Research strategies

Focus group

The focus group was used as a participative research technique, which is sensitive to data collection by means of collective interactions about one or more focus topics suggested by the researchers, enabling collective constructions and perceptions, attitudes and representations in a specific context to be understood^{9,10}.

The researcher takes on the role of moderator of the debate and of the interinfluences game, modulating opinions and positions regarding a specific subject. Conducting focus groups, either alone or in combination with other data collection instruments, has proven to be useful in health research to capture the complexity of the research object in its dynamic and processual aspects¹¹.

In this study, data collection took place through the focus group and auxiliary methodological strategies, used as facilitators, namely: integrated panel and community journal.

The integrated panel is a participative instrument that promotes communication, participation, cooperation and knowledge integration between the participants. It is a strategy to apprehend answers from people in society regarding previous knowledge, as well as to aid in identifying the construction of new knowledges, perceptions and positions on a specific subject⁹.

The group is divided into subgroups of two to six participants, and to each subgroup the researcher hands previous elaborated questions. Each participant, as they get acquainted with the answers from the other subgroup(s), can bring up reflections and changes, build and update knowledges and opinions. The goal is to integrate concepts and knowledges, and it can be used to insert subjects into the debate, to integrate the group and the concepts, ideas and/or conclusions produced, ensuring the involvement of everyone and bringing the participants closer to a specific focus subject¹².

In the focus group, the integrated panel was used, then, as an instrument to diagnose the parents' previous knowledge about work of the CAPSij team:

differences between specialties that make up the team, speech-language-hearing listening and care.

At this stage, more directive issues regarding the teamwork were dealt with:

- Did you know you are attended by a team? What did you know about it?
- Did you know the team discusses the cases, the therapies, strategies and referrals? What do you think about it?
- What do you think works well in the teamwork?
- What aspect of the therapeutic work brings about more results? Why?
- Does it always work? Does it work sometimes? Can you give examples?

At a second stage, questions on the perception of the specialties and on the speech-language-hearing work were approached:

- Can you distinguish the work of each professional from the team: doctor, psychologist, speech-language-hearing therapist and others?
- If so, why? How? Examples?
- How do you see the speech-language-hearing work: individual, group care? What do you notice?
- Do you think the speech-language-hearing professionals understand your and your children's needs? If so, does the work of the speech-language-hearing therapist make any difference? Why?

In the second meeting of the focus group, the community journal was developed and used as a strategy to promote the debate and to build collective memory and narrative of the arrival of the parents in the CAPSij and of the perceptions and experiences about their children's care with the team and, particularly, with the speech-language-hearing therapist. The community journal counted with cuts and pastes from magazines and with texts written by the participants. The narratives elaborated when the journal was produced were also considered corpora of the paper and, in the results, excerpts of this material compose synthetic descriptions of the group's statements.

The community journal is a collective product and, when used as a facilitating strategy for data collection procedures, it has simultaneously the informative and the reflexive role concerning specific problem situations¹³.

The data were analyzed following Bardin's content analysis stages: pre-analysis, floating reading of the videos and field diary; preparation of the material; construction of the gross data (corpora) with analysis

dimensions and directions; treatment of the material and establishment of rules for clippings, followed by categorization and encoding of the material, which was done in thematic axes, with the analytical categories and subcategories:

Category: parents' perception of the care given by the team.

- Subcategories: parents' perception of case discussions and team conduct; and parents' perception of each specialty's differential.

Category: parents' perception of the effects and results of the care at the CAPSij.

Category: parents' perception of the speech-language-hearing care at the CAPSij.

- Subcategory: parents' perception of their being listened to.

The selection of excerpts of parents' speeches, to be present in the results, was conducted with the following criterion: that it be a representative synthesis of the group's discourse, i.e., directly expressing the elaboration the group managed to do about each of the subjects approached. It means that it was not sought to apprehend exhaustively the individual perception of each parent, but the collective perceptions and positions that made up a group narrative of the focus subjects approached.

Subsequently, the excerpts of the participants' speeches were categorized correspondingly, as in the diagram below:

RESULTS

In the care dynamics at the CAPSij, where the research was conducted, the parents of children with ASD present, as one of the main complaints, the difficulty of communicating and interacting with their children; consequently, they also ask for the speech-language-hearing therapist's intervention. Seeking for specialized treatment, these parents had already gone through other attention centers of the SUS network and, in this process, the expectations for speech-language-hearing intervention are recurrent, as it will be seen below.

Category: parents' perception of the care given by the team.

In the parents' perception, the team supports and makes clear that, in spite of the child's difficulties, the parents can and should believe in their children's development and autonomy:

The team helps very much concerning stimulus, targeting. They open our minds to accept our children and encourage them. We came to have more knowledge after getting in touch with the team. Then, all the stimulus given was driven by the team. We give continuity because we were motivated and taught by the team. (Participant 4).

For them, the care offered by the CAPSij team is also fundamental to the process of accepting the ASD diagnosis. In the perception of participant 7:

It is a new experience. We are simply hurled a diagnosis, a diagnostic hypothesis.

The parents' group at the CAPSij gives support even on the small doubts.

It was the group therapy proposal, in this case the family group, that gave support to the mother in the statement above. This type of support is one of the singularities pointed to in the relationship between parents and mental health team.

In the following description, a mother (participant 7) indicates that the treatment proposed by the team is clear and objective, aligned with the child's needs, which would reflect on this mother's relationship with her son, as well as on the child's development.

I don't know if it happens with you (other parents) too, but, because of my child's problem, I'm not often invited to parties, birthdays, right? They always say: "Hey, here comes the trouble. He's going to knock everything down!" We get upset.

The team welcomes us and calms us down; they talk about many situations and explain the treatment! They work on the children's difficulties; for example, my son is afraid of the balloons in the children's parties, and this is dealt with in therapy. They (therapists in the group) say: "No, it's not going to hurt, bite; it won't pop, it won't hurt you..."; so he manages to come closer to the balloons and overcome his fear.

In another moment, another mother (participant 6) gives examples of her difficulties, her family dramatic situation, highlighting the guidance and listening she was given:

S. came to CAPSij, he was already four years old, he was older, right? Then, they welcomed me, counseled me on breastfeeding. S. still wants to breastfeed, he's big and he thinks he can breastfeed. We tell him "no", but saying no to him brings tears and pain, he has a hard time with the word "no". If you say "no", he cries endlessly. The therapist (reference-professional) said: "mother, he has to learn that no is no. It's going to hurt you, he is going to cry, but it's important to him".

It is interesting to observe that when this mother is called to help the therapist, so that she can help her in turn, the mother enlarges her repertoire and qualifies her position in her son's treatment, leaving her condition of knowledge receiver and moving towards a greater autonomy in caring for the child.

It's a different world for us.

Sometimes I take notes of what they say, so I won't forget. Here they won't say: "Oh, you're dumb, you can't do this". They will never say this. She (professional) told me: "We are going to help each other. Mother, you talk to me about whatever S. needs and we're going to help". I notice when he can't speak, cries a lot and suffers. I tell her (professional), who says: "Mother, try this, look at him, this way, that he's going to be better". There are some situations that she tells me what to do, I do it and see him get better.

Subcategory: parents' perception of case discussions and team conduct

The parents identify that there are discussions regarding the cases, conducts and clinical decisions, guiding the construction of the therapeutic projects, they say, for instance:

They discuss to see in which therapeutic group they (the children) will get into. (Participant 2).

Even without the technical knowledge of what is a unique therapeutic project, the parents recognize that there are criteria for including the children with similar needs in therapeutic groups; inclusion guided by team discussions:

It is a way for them (professionals) to observe how each child is. I've noticed that J. has a group, I think they are six small children two, four years old, up to his age. But they (professionals) observe everything and keep together the children for whom they have the same goals to work on. (Participant 7).

Again, the co-responsibility in the treatment and the acknowledgement of the technical work developed by the team come up. In the words of participant 4:

There is a form we sign when we bring the child here, if we agree with the norms of the treatment. By agreeing, we help the team do the work. It is important to deal with something you are aware of and signed. It's written, and you can't say: "Oh, I didn't know it!", or "I don't know", since you do know, right? So, you have to deal with what you have signed. I found this form interesting because it has a part that goes somewhat like this: "If it is necessary, we will give instructions at school and at home as well". This is like private attention, because I came to taking J. to private care. They (CAPSij team) went to my child's school to see what his process was like there, and whether it was structured to receive my child.

Subcategory: parents' perception of each specialty's differential.

The parents not only notice the composition of an interdisciplinary team in relation to the work at the CAPSij, but also recognize the different professional specialties.

We know there are specialists: speech-language-hearing therapist, psychologist... There's the guy from the pharmacy. He's always in touch. There's a nurse along. There's the social worker...

The psychologist works for the parents, right?

I think the psychologist helps us open our minds and understand, so we can pass it on correctly to our children. Yes, they (the psychologists) give us support and knowledge. The psychologist helps more the parents, he prepares us. I've noticed the organization in J. and in me also. (Participant 4).

We're getting to a consensus that the psychologist was more straightforward with us than with the children. They're very attentive, right? They pass on to us what we have to do. (Participant 1).

Yes, we improve. Mothers that sometimes think: "Oh, my child is special, let me do what he wants". We learn that our children need to be treated as children. Regardless of being special, they're children. (Participant 7).

The speech-language-hearing work, in the parents' perception, are centered and highlighted on the interventions with the children. Here the disciplinary core

is called to compose the care, hybridizing their knowledges and practices with the other specialties. In the words of a mother:

In my opinion, the speech therapist is the greatest need, the others coming behind them. The speech-language-hearing therapist is crucial. They can't be missing in the child's development. Now, my son is beginning to have a dialogue. He took too long to talk; he was almost two when he began to talk. It was very little, but he was talking. He would point to something and I'd ask: "What is this?", and he kept pointing. I'd say: "What do you want?", and I'd wait for him to say: "Water", and only then I'd give it to him. (Participant 7).

Category: parents' perception of the effects and results of the care at the CAPSij.

The CAPSij gave my son a good basis, because that's where he began to develop rules, routines. The CAPSij helped him very much become who he is today. Children with autism don't have rules, don't have routine; or them, whatever they're doing is "right" and that's all. (Participant 8).

It is interesting to mention that, when the mother said the words above, another mother manifested that, with the people she is close to, it is always necessary to sustain her position in favor of the treatment received at the CAPSij, denying the premise that the natural course of development could be enough for her child to overcome the difficulties. In this sense, a father also pointed to such issues:

If it were in another place, he'd probably not have gained so much. Many people I know say: "Oh, he's going to get better; you don't have to take him there". But no, the child has to have treatment, but they don't understand. For my son, it was very good to have this basis here at the CAPSij. (Participant 6).

The following excerpt shows the parents' perception of the CAPSij as a safe place, also recognizing that there are professionals who can handle the situations involving the children.

When V. is here, he doesn't want to go home. (Participant 4).

J. doesn't want to go either; he loves the playground here. When he comes here, he wants to stay; he doesn't want to leave; he asks: "Just a little bit more". (Participant 7).

E. goes on top of the rock (there's a rock in the playground at the CAPSij). I let J. be a child here. I let him do what he wants, because it's very safe here. (Participant 7).

The team doesn't say "no" to my son all the time. (Participant 9).

The groups, at this CAPSij, are formed according to therapeutic goals. The children are included, respecting criteria such as: UTP therapeutic goals, personal characteristics (size, age, etc.) and school schedule.

The group therapy helped my son very much. Staying with children the same age, and younger too, was excellent. Some qualities the children have influenced him, and his qualities influenced the children. (Participant 4).

It's a way they (professionals) can observe what each child is like. (Participant 7).

The parents recognize that the groups are important spaces for the children to elaborate and learn with each other, that it is through the experience of playing together that they develop both subjectively and cognitively.

There was a day in J.'s group when he was participative, playing with all the children. There was a girl who was quiet and who didn't want to share toys with anyone. J. came closer, took her a toy. She didn't want to share, but he came closer little by little, and the interaction between them happened: the girl agreed to share the toy.

The mother said: "My daughter is very quarrelsome and doesn't share toys". The psychologist of the group was very wise and said: "She is going to make it; they're going to help one another. That's what the group is for, mother". (Participant 7).

The clippings with individual actions gain effect and outline in the group, also due to the therapist's mediation in the field of language, enabling the parents to look to their condition as children, which transcends the pathological conditions.

He (the therapist) is right. Guys, it's a child wanting to play with another one! It's a child, special or not, it's a child. They have to interact and exchange experiences. (Participant 7).

Right. Exchange whatever they have to exchange. They're children and we will let them be children. I

loved it that the psychologist said this. (Participant 7).

In the following statements, it is possible to notice transformations based on the work performed by the team. The listening here is enlarged to include the possibility of better understanding the way of being and (re)positioning oneself in the relationship with the children.

The team makes our world better, more accessible to our children; they make it much easier. They show a more direct way to reach our children. I think I have clearer talks with J. since I came here. I used to say a lot of things and J. wouldn't understand anything. Then I started to see that, the simpler I was, more my son would understand, and better. (...) This thing of speaking and looking in the eye I've learned here, too. I only spoke loudly and looking down. I only yelled: "J., be quiet!". I've learned that this doesn't help; it is necessary to get down and speak looking at him. (Participant 7).

Category: parents' perception of the speech-language-hearing care at the CAPSij.

It is perceptible how the speech-language-hearing disciplinary core is present in the care for these children.

I think the speech-language-hearing therapist helps a lot with language. It's usually what the children need most. Being proficient in language, because that's their deficiency. In my opinion, the speech therapist is the greatest need, the other coming behind them. The speech therapist understands the communication needs we and the children have. (Participant 7).

The speech-language-hearing therapist at the CAPSij works with the parents, for example, about supplementary and alternative communication, bringing instruments, strategies, and manners of handling language through resources that are not only verbal.

The speech therapist helps us communicate. In a natural way, my son is learning to speak. When they don't know, they make gestures and point: "I want, I want!". But, what does he want? That's when the speech therapist comes in and helps us with the words, gestures and behaviors, because all this gets into communication.

And you, who are a mother, will also stimulate and ask: "What do you want? Do you want this? What is this?". Because he knows what he wants but doesn't know how to say it. Even if he doesn't know the word, for example, you say (mother holds up a pen): "This?" "It's a pen". You say and show what he wants. I see the speech therapist this way, as a cleaner channel to develop communication. The speech therapist will help you develop speech and we'll continue the work at home. (Participant 4).

In the statement below, it is possible to observe that one of the mothers speaks about her experience with speech-language-hearing in the context of the CAPSij and that the results are, up to a point, more related to her position and perception than changes in the child's speech itself, although these were also happening.

It all began with the speech therapist; I saw he was learning to communicate. I didn't even know J. could sing! (Participant 7).

Subcategory: parents' perception of the clinical listening in the speech-language-hearing care.

There is a refined perception here: recognizing that, even not speaking, the child is in the language and under the effect of the mother's speech. This also is communication.

The speech-language-hearing therapist understands our and our children's needs. My son doesn't speak; it's not because he doesn't speak that he doesn't have a language and doesn't understand. He understands everything I say, and he doesn't speak. The speech therapist helps and shows it to us. (Participant 2).

In the words of the relatives, the speech-language-hearing therapist's listening to their questions and needs enables the child to be perceived as a subject and, therefore, a dialogic condition.

The speech-language-hearing therapist is essential because the children with autism have a hard time speaking. The speech-language-hearing therapist showed me that it's important to talk to my son. She teaches simple, day-to-day things. He learns that it's his turn to talk, and his turn to listen. He gains rules and understanding, things my son didn't use to know, and it helps a lot. And no one values it. These are small things that make a big difference. (Participant 1).

DISCUSSION

In the parents' perception, the care provided by a team create bonds, learning and concrete improvement in their relationship with their children, aiding them to face the difficulties imposed by ASD.

It is a fact that they see it as a place of belonging; they feel listened to and valued by the team. They recognize a field of care in the team's availability and implication.

In the proposal of the CAPSij, the care gains a listening space that furnishes understanding about the processes that make one ill or that intensify the symptoms; about the children's specific needs regarding, for example, delay in speech; regarding the sensorial, cognitive and behavioral disorders. But it also identifies, along with the families, the children's health powers, that which they can do and know how to.

The listening, as part of the care given by the team, appears as a power of the bond between therapist and mother/father – team and parents; it appears also as a co-responsibility with the interventions performed by the therapist, whose result would be visible in the child's improvement.

As mentioned above, the greatest demand for attention at the CAPSij researched is of children with ASD, which makes the unit's institutional therapeutic project more directed to this public. It becomes evident that, for the parents, the psychologist is a type of teamwork managing "center", an articulator in the field of mental health. The professionals of the other disciplinary cores work with this backup. This means that the parents recognize the field of mental health and its different knowledge cores, the specialties.

Concerning the work with the children, the parents' statements indicate predominance of disciplinary work, and relate the other specialties to the work done directly with the children's difficulties and symptoms.

At the focus group meetings, the parents' perception of the effects of their children's treatment was unanimous. They knowingly and appropriately describe achievements in social interaction, in establishing routines, in the process of subjective constitution and in language acquisition.

In the protected space of the therapeutic setting, which the CAPSij configures, the parents reach confidence relations and perceive that exchange and interaction between the children in the therapeutic group produce care and enlarge the social and communicative repertoire.

The team oftentimes provides to the parents a new situation of contact with childhood, showing the naturalness of the child and diminishing the weight of the marks linked to the ASD. Vicentin¹⁵ says that “the services that work allied with the art of being a child need to be alert to the effects production that the poet Leminski suggests we learn with the children: joy, activity and the ability to fight for what you want”. It seems like it is something like this that the parents notice in the work of the CAPSij. Indeed, studies corroborate the importance of the therapist’s role in the construction of facilitating actions for changes in the patients and their relatives, by means of safe relations of support and learning experiences, and of the composition of collaborative partnerships^{16,17}.

The speech-language-hearing therapy, in the team, seems to have a prominent place for the parents, in the reasoning that the communication difficulties are a significant part of the symptoms of the children with ASD. The parents recognize social inclusion in the language. Indeed, it is fundamental; the language enables social relations and participation.

Given the importance of life and social bonds, it is possible to have a speech-language-hearing work that uses language as a power to recognize the other and to have social interaction, which is different from signifying the speech-language-hearing work by the fight against a supposed absence of language in the child; supposed, because there always is language, even with a possible absence of speech or intelligible speech. Evidently, the absence of speech can intensify the psychic illness, but it does not limit the work.

The parents modify the quality of the communication and the relation with their children on the therapeutic experience with the speech-language-hearing therapist, and become more linguistically open and interesting figures to their children, because they understand the dynamics of communication and feel effectively instrumentalized to work it with the children.

The speech-language-hearing therapist seems to create possibilities for the parents and other caregivers to qualify their investment on the communication with the child. When thinking of the clinical hearing as producing effects on the subject, some statements point to a caregiving and transforming speech-language-hearing clinic.

The parents come to realize that communication goes beyond speech and, therefore, can mean the children’s gestures, looks, facial and bodily expressions as language, improving the quality of the relations.

The fields of treatment outlined for the families of these children with severe psychic problems bring various sufferings: from the mourning for the idealized child to the discovery of these children’s little progresses, and to changes in these families’ way of living, which leads to a reflection on the tenderness of the listening and the care to be offered. The emotions the parents present when they receive their children’s diagnosis, going from the impact of the initial news, through denial, culpability, anguish, anger, and concerns about the child’s future are not negligible, and that means a tough walk until getting to the stage of acceptance of the diagnosis and its implications^{18,19}. The listening in this process is crucial for the family and the professionals to build early and sensitive actions and strategies in the child’s treatment.

It is evident that the parents perceive the concrete instrumentalization of the ways of dealing with the children as care, and so do they regarding the legitimization of their difficulties and suffering. It is here that the construction of therapeutic groups gains even more relevance, above all to build safe spaces where the specialist shares their knowledge in a true partnership with the parents, whose strategies can aid the childhood and adolescence services¹⁷.

The work of the speech-language-hearing therapist is not only here. We have to continue it for the cycle to be completed, right? She teaches us to teach the child at home; so, we give continuity to it.

And there are fathers who give up, because they think it’s too much work to get home and play with the child and stimulate them. (Participant 4)

It is noticed that the children feel empowered when they are able to look at their children and recognize characteristics inherent to childhood and development possibilities. Thus, it is necessary to offer enlarged care in these cases, which leads to a professional displacement in relation to the strict disciplinary perspectives and, simultaneously, an openness to interdisciplinarity, which begins with the gesture of taking on the cases as generating center of each and everyone of the decisions about the health care.

The statement just made does not correspond to an isolated situation. A study conducted with parents of children from zero to six years old, attended at pediatric rehabilitation in Ontario, Canada, verified the parents’ perceptions and expectations regarding the rehabilitation service in their children’s occupational therapy, psychology and speech-language-hearing. The

authors identified four axes related to the expectations of the treatment: (a) expectations related to the child's therapy, (b) the institution and the services offered, (c) the therapist offering the services, and (d) the parents themselves. It was observed, in the categories (b) and (c), that the parents' expectation regarding the rehabilitation service consisted in the aspiration for a quick solution for their children symptoms. However, the therapists helped the parents get involved in the sessions and showed them they could develop the recommendations at home. The study concludes for the relevance and the centrality of positive therapeutic relations and the family-centered therapy, which contributes directly to the children's overall development²⁰.

In other words, it is about legitimating the family as an integral part in the therapeutic process, and not only as a supporting role or a passive receptor of the work. According to Oliveira et al.²¹, the family guidance has social implications, since the parents become multiplying agents, contributing to disseminate the information discussed with the various interlocutors the child has. In this sense, the group therapy practice involving the parents ought to provide a safe environment where the qualified listening can take place regarding the needs of the children's families or guardians, ensuring the effectiveness of the intervention, which implies in listening beyond the literalness of the complaints and symptoms; listening to what hasn't been said²².

For the speech-language-hearing therapist, whose work focus is on the language difficulties that appear in the complaints the families bring to the CAPSij, the bet is on not taking them literally and by means of prescriptive attitudes of how to do this or that. On the contrary, based on a qualified listening (though instrumental guidance be also necessary), the speech-language-hearing therapist may involve the parents in the therapeutic process as coauthors of the care.

This being so, it is up to the speech-language-hearing therapist to provoke the parents regarding the way they see their child, towards making the child a legitimate other, a valid interlocutor.

I started noticing the absence of speech, because, being one year and six months old, she wouldn't say "mommy", she wouldn't say "daddy", she wouldn't ask for water. My mother-in-law used to tell me: "Her father started talking when he was four; her aunt started talking when she was six", and I didn't think that was normal. They (the in-laws) thought we were being crazy. They thought it was a silly thing:

"She will soon start talking", they'd say. But it's not just the speech, you understand? She doesn't talk straight out about the things. She's very repetitive, very smart, and she observes everything. She does many things. But she also doesn't do a whole lot of other things the children her age do. It's not that we are comparing, but we see the limitation, especially when she gets together with other children in the classroom. There was a party in the spring with a dance to which she didn't go. She wasn't throwing a tantrum; she behaved as one who didn't see the purpose in that. And that's when it should be stimulated, should be treated, should be thought of as a means of communicating, right? (Participant 9).

For Pereira and Keske-Soares²³, the listening needs to consider the subject before any symptom, since the "subject requires something more than a biological cure, and the symptom itself is a subjective production, and it can only be considered from an ordered position through language".

The speech-language-hearing configured, then, an otherness for the parents to think about the clinical listening and the cares offered at the CAPSij, in the sense that the focus on the disciplinary core of the speech-language-hearing worked as a type of mirror for the other disciplinary cores in the field of mental health and, at the same time, as a parameter to think about the permeability of the teamwork to the inter- and even the transdisciplinarity intended, though not always reached in the health practices.

With some frequency, the reality slides back into the still dominant tendency of fragmenting the care practices by specialties and technical specialisms, turning the teamwork into a sum of the parceled knowledges, a transit of referrals and choices for techniques and procedures from this or that professional, even when the professionals do not want this to happen.

Submitting to analysis a disciplinary core through talks with the parents of patients offered the opportunity to observe up to what point and up to when the team and the speech-language-hearing manages to effectively hybridize knowledges and practices, and in what situations and contexts they did not.

CONCLUSION

In the parents' speech, the effects of the clinical listening offered by the team are clearly perceived, especially by the speech-language-hearing therapist, throughout the care processes; such a listening that

affected the understanding and the positions of the parents towards their children. This agrees with the presupposition with which the article was introduced: the ways the children are perceived and interpreted by their relatives collaborate, indeed, with the systematization, on the part of the health professionals, of theoretical, methodological and procedural knowledges on how to handle the ASD; and, moreover, they include the parents in the treatment, potentializing their conditions to personally elaborate on their children's problems, which can also aid in qualifying the relations with their children.

If this is up to the speech-language-hearing therapy, it is equally up to the other disciplinary cores composing the teams at the CAPSij, since, far from any illusory disciplinary hierarchy, the opening of the disciplinary borders seems, to some degree, to have already permeated into the mental health work processes, which does not invalidate the disciplines; instead, enriches them.

The clinical listening and the team production of care are collective processes that potentialize the openness to the other, to the difference and to the ability to face the health/disease processes with the participation and centrality of the users, in the health practices. Collectively and interdisciplinarily improving the care resources and strategies as based on listening to the users, has proved to be adequate to institute and/or consolidate the advances in the SUS care policies, especially in terms of integrality and equity in health. The possibility of reading and systematizing certain dimensions of the teamwork at the CAPSij based on listening to the parents of children with ASD, as done here, seems to have attested to it.

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