THE FAMILY'S PERCEPTION OF SPEECH THERAPY IN AN OUTPATIENT UNIT

Percepção da família em relação à atuação fonoaudiológica em um ambulatório

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ABSTRACT

Purpose: to understand perception of the family towards outpatient Speech facility. **Methods:** qualitative research method using semi-structured interviews to collect details. The samples/research was done with six parents/legal guardians, inside the outpatient speech facility, in a Public hospital, located in Curitiba. The pre-established criteria used to choose the ones that were going to be part of the research was related to the patients that were going under a treatment over a five months period, coming once a week to the Hospital, and having free time to be part of the research. The method used to treat the data obtained, was a thematic analyses identifying itself in the Attending category, with the following subcategories: acknowledging the service, linkage and medical practices. **Results:** it was identified that parents/legal guardian had limited knowledge about Speech Therapy; the fragility of these families; the need of having a link process with these families, recognizing the activities developed by them. **Conclusion:** concerning each family group singularity, the interaction between the families and professionals helps the therapeutic process, encouraging and developing self-confidence of patients, creating a link, essential for parents participation.

KEYWORDS: Family; Speech, Language and Hearing Sciences; /therapy; Humanization of Assistance

INTRODUCTION

A closer relationship between the speech therapist and the patient's family as well as the exchange of information help to produce a partnership that is essential for the effective delivery of care. For a long time speech therapy was based on a technical approach in which the pathology (a communication disorder) took precedence over the individual and his environment[1]. In therapeutic practice, the relationship with the family traditionally started at the initial interview, when data related to the child's developmental history was collected. The parents were then called after the assessment so that the results could be shown to them. Any other meetings were considered orientation meetings and usually arranged in order to teach, correct and inform[1].

Orientation meetings for families are still part of speech therapists' procedures and play an important role producing disseminators of therapeutic guidance, thereby ensuring that the information discussed is transmitted to others[2]. However, such meetings need to be constantly reassessed by the speech therapist, who should look for new meanings[3] for each new situation, avoiding a predominantly authoritarian[4] discourse that rules out the possibility of reversibility, which is understood as the exchange of roles in the interaction that constitutes the discourse and which the discourse constitutes[5].

A closer relationship between the speech therapist and the patient's family and the way that the speech therapist delivers care are intimately associated with how clinical care is understood. Two clinical models can be identified: one based on objectivity and another based on subjectivity. In general terms, the former seeks to investigate, observe and correct existing changes, while the latter aims to understand and interpret the subject's history in order to help him recover[6]. Listening to the patient in his subjectivity and a knowledge of his

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social context help to individualize the care provided and bring a sense of completeness marked by notions of reception to the care process[7].

Based on the assumption that all health care workers perform clinical work in one way or another[8], it is fundamental to understand what the clinical space represents. The environment constituted by the clinical space allows the production of attitudes that are essential if health care professionals' practices are to turn the space into one where there is a sense of reception[8,9]. This receiving, which represents welcoming and listening to people's needs, seeking ways of understanding them and socializing with the family[10], has a broad meaning of humanization. However, humanization can only be practiced if there is the possibility of continual open dialog embracing the relationship between subjects and their needs[11].

The concept of humanization has occupied a place of prominence in current proposals for restructuring health care practices in Brazil in terms of making them more complete, effective and accessible[12]. Humanization also covers the transformation of work relations based on individual effort and interaction and cooperation among the whole team. The humanization of health services requires changes in structures, practices and, also, people[13]. These changes in turn require that the health care professional learn how to view the patient or user in a new way that is not limited to how the care is provided but extends to how the patient is seen in his relation with the world as an individual[14].

With the inclusion of speech and language therapy in the *Sistema Único de Saúde* (SUS, the Brazilian national health care system), many concepts and practices have been reassessed in order to offer a quality service in line with the precepts of public health[15,16]. Speech therapists who work in public health in Brazil need to be familiar with issues that are of relevance to the SUS[17], as only then can they plan their activities and ensure these comply with the needs of the population being cared for, thereby improving the quality of health services provided to these users.

The change of attitude in the health care professional/user/family relationship favors greater closeness between the subjects, which is essential to ensure bonding between them; however, this bond can only exist if the user is seen as a subject who talks, judges and has wishes[18]. A bond increases the effectiveness of health actions and stimulates user participation in the provision of the service, promoting user independence and citizenship[18]. It can be considered a therapeutic resource, where therapy is understood to be an essential part of clinical practice that studies and puts into practice suitable means of curing, rehabilitating, relieving suffering and preventing future harm[19].

Working on the premise that family involvement and participation are fundamental throughout the whole therapeutic process, this study seeks to understand the family's perception of speech therapy in an outpatient setting.

METHODS

This study was carried out as part of the Masters Program in Health and Occupational Management at the University of Vale do Itajaí and complies with the guidelines and regulations governing research involving humans stipulated in Resolution 196/96 of the National Health Council. The study was approved by the University Research and Ethics Committee under reference no. 115.972 and by the Ethics and Research Committee at the hospital where the investigation was carried out under reference no. 154.325.

The study is a descriptive study and uses a qualitative approach in which semi-structured interviews were used to collect the data. The sample consisted of six individuals responsible for children being seen in the speech therapy outpatient unit in the physical medicine and rehabilitation service of a public hospital in Curitiba, Paraná. The patient is seen by a speech therapist when he is referred for a consultation by the institution's physician.

The authors' initial intention was to use a sample of nine parents of children with oral language impairment seen in the outpatient unit. After the inclusion criteria were applied (having had speech therapy for more than five months, attending weekly sessions and being available to take part in the study), six participants were left in the final sample.

After this initial selection, invitations were extended to parents, who were given the option of either the mother or father taking part in the study. Each couple chose the mother because of her availability and because she was more involved in the consultations.

Four mothers were in the 30- to 50-year age range and two in the 20- to 30-year range. All had two or more children, one of whom had complaints of speech difficulties. They had been referred by other services in the hospital.

For the information-collection stage, the interview questions were structured to allow a discussion about the first sessions, what it was like for the family to know that their son would need to be seen by a speech therapist, the beginning of treatment and the conversations during treatment. The choice of subjects used in the interview (Annex 1) was based on the objectives that had been formulated for the study.

Appendix 1 – Interview Questions

1. How did you come to use this hospital? And the speech therapy service? What services do you and your family use in this hospital?
2. When did you find out that your son/daughter would need speech therapy? How did you and your family react to this?
3. What was the start of the treatment like for you? Do you consider this treatment to be different from others that you are familiar with? Why? Did you have a lot of questions about it?
4. What do you think of the conversations between you, me and the other family members? Tell me what you think is important about these meetings.

The data were analyzed using thematic analysis to discover the unit of meaning in the communication by observing the presence and frequency of the object in question[20]. To ensure their anonymity, participants were identified by the letter I (interviewee) followed by a number (from 1 to 6).

The category "care" was then divided into three subcategories (recognition of the specific nature of speech therapy, the bond with the speech therapy and the production of new practices) using sections of the interviewees' responses as recording units.

RESULTS

Recognition of the specific nature of speech therapy

It can be seen that when they arrive for the speech therapy sessions, the families compare their expectations based on consultations they are familiar with and what they consider important with what they find. This perception then leads to the possibility of establishing a bond and deciding whether to continue or give up the therapy. Greater closeness between the health care professional and family based on respect and trust favors the interweaving of knowledge and practices developed during the rehabilitation process.

When families arrive at the service, they each have their own set of needs and particularities that need to be understood by the health care worker. The moment when the family arrives to start the sessions represents the beginning of a gradual process of knowledge exchange during which the family gains a better understanding of the treatment, as can be observed from the following comments:

I3: "I didn't have much idea what the treatment was like".

I1: "And even for him the sessions were different because he also thought it would be an appointment with a doctor."

A hospital outpatient unit is popularly considered a place where people can see a doctor. The treatment prescribed by the doctor is normally carried out by the user himself, who follows the prescribed recommendations, and is then followed up by means of prebooked return appointments at somewhat irregular intervals. But in the speech therapy outpatient unit in the hospital where the study was carried out, the procedures are different, which surprised the users:

I1: "I could see that it was different.. I would never have imagined it was like that. It was treatment rather than a visit to the doctor."

I5: "It's different. It's every week. It's not just a visit to the doctor."

As the family becomes more familiar with the service, they begin to compare it with other visits to see a doctor or receive treatment. This is confirmed by the mothers' comments:

I6: "It was always something very relaxed. He thinks of it as entertainment, very unlike a clinic. I think it has to be like that for children, with this sense of entertainment."

I1: "Well I was used to bringing him and having to wait because I used to bring him to see the psychologist."

Recognition of the service and the specific role it plays can also be seen in the comments about the children's behavior:

I6: "He's different when he comes here. He doesn't look like he's coming to hospital for treatment."

I3: "He reminds us that he wants to come, and we bring him."

On other occasions the change in the child's behavior shows the family how important it is to continue the treatment:

I3: "We can see that he's happy when he comes here. It's good for him. When he went a while without

coming, he would ask, he got bored at home and he said that he had to come here."

I1: "Everything that he likes happens here. I like it because I ask him, he tells me and I know what he likes."

The comments show that during the therapy, and because of it, the families constantly evaluates their child's progress, and based on these perceptions the decisions taken by the families acquire new meanings:

I3: "It was good that we brought him because he has made progress. He is more independent. Now he defends himself and before he was very withdrawn."

I2: "So I brought him here and, my goodness, he's improved a lot. He even passed to the next grade at school. He's happy. Before he used to mix up words. You saw, didn't you? He would get angry. Not any longer, heavens above, now he even talks too much."

I5: "I think everything is fine. He has made quite a bit of progress, he's speaking better."

Bonding

The stimulus to continue taking part in the treatment begins to appear in the comments as the health care professional, child and family come closer to each other and develop a bond:

I6: "Also because it's a question of trust. He likes it and I found it very positive. There has to be closeness, friendship, and it's like that with the speech therapist. He never said he didn't want to go."

I2: "I've never missed a session here. I missed some when it was raining a lot, but I never stopped. I think it's great. He has got a lot better, much better."

I5: "Ah! I like it, I think it's really good. Because if that's what he needs than that's what we've got to do. That's what I think, you know."

As the speech therapist calls the family and the sessions continue, different issues are worked on. Sometimes the conversations are intended to be informative:

I4: "The explanations were very important. They helped me change the way I behave with him at home. Because if I didn't have the sessions, I might play with him a bit. But only very rarely. Now I know what is important for him."

I6: "And as you spoke with me I knew all about what was happening, and we would then do it at home. If you know how to help me, if you have someone to help you, I can do it."

At other times the conversations highlighted the importance of cooperation:

I1: "When you started to call me, you got me involved in the whole thing, I could see that it was important, you already needed me there. So I saw that you needed me to take part, you know. So I saw that he also needed me, he needed my participation as well. That was when he started to get better because he saw that I was more present."

I2: "Our conversations? They're part of the treatment and they helped me a lot**. I've started to help him more.** I bought a lot of books and games. It's all at home. He doesn't damage anything. He plays with them and puts them away."

I6: "I think it's great. I see what it's like working together. We always talked together a lot. So I think this dialog is excellent because we know what's happening. There is an exchange. I like this closeness. And he always liked coming here. And that was always a good sign for me. Because if he liked coming then it was because it was good for him, and I could see that the partnership between you and me was working out."

Conversation opens up a channel that not only brings people closer together but also provides moments when there is reflection and behavior is reconstructed, strengthening the links between all involved:

I5: "You do your bit, you're helping him. You are patient, you talk to me, you explain things to me. We are the ones that don't help a lot. It's like I say, having a child at this age..."

I3: "It was difficult at first accepting that he was not speaking properly and that we needed to change the way we dealt with him. But I began to realize that he needed to grow, to develop.

Therapeutic practices

The comments show that the increase in self-confidence stimulates participation and involvement in therapeutic practices. Each mother has her own procedure that needs to be recognized and appreciated so that her individuality is respected. In some cases, the mothers are more dependent on the health care professionals to know what to do:

I6: "I did everything that they taught me, everything that I was asked to do, I did everything just right, everything. You guided me, showed me what I should do, how to stimulate my child, and that's what I did. I think that it involves a lot of responsibility on both sides."

I2: "It helped me to be more patient with him. To guide him. I started to read more with him, and that helped me a lot. I started to learn more too."

In other cases the family's independence helps the child in different situations in the family space and when he or she is in contact with others socially:

I4: "When I leave here I give guidance to my mother, my mother in law and the others too. I don't want them to talk incorrectly to him. My role is to try to continue what is done here."

I5: "I try to give him a boost, to make him feel secure."

I3: "Sometimes I watch him so that I can interact better with him."

Family involvement and participation produces information that shows there is an interest in improving therapeutic practice on both sides by interleaving and exchanging knowledge:

I5: "I think everything is fine. He likes it. There is nothing that you can change. I think it's me who has to change."

I6: "I think that when you're going to add something, a different exercise, you should show the mother so that she can learn with you and really help at home. This is a weak point that could be changed. I think that with a child that's also true for writing or anything else. Do it together."

The comments show that combining practices favors understanding, stimulating and reformulating the way things are done:

I3: "We learnt to give him the time he needs to talk. To respect his personality. To respect him more and not to keep comparing him with his brothers and sisters, who are quicker. To give him the time he needs to do his things."

I1: "He would come to tell me about things at school and I would say, 'Oh, you're taking a long time. Get on with it!' Now I listen. He's not to blame for the things that happen to me. He depends on me if he is to get better."

I4: "Now I know what is important for him. And I do it every day. I've started giving him more appropriate food. Carrots, apples, pears, fruits for him to chew rather than just papaya and juice. I'm giving him meat in larger pieces."

The conversations during therapeutic practice are considered opportunities for giving vent to feelings, reassessing and reinforcing attitudes:

I5: "I think it depends on me. Tolerance. I think I'm already getting better, I'm trying."

I1: "To be honest, the treatment was good for me as well as for him. Because I started to understand things better. I started to see things differently."

DISCUSSION

Regardless of the place chosen by the families for the speech therapy, the comments highlight the moment when they were faced with the new and when they registered their first impressions, made comparisons and adopted positions. The arrival at the health center is the moment when the family meets the health care professional. Users of the services complain not about a lack of technical knowledge when they are being seen but about a lack of interest and willingness to take responsibility on the part of the staff'[21].

During the course of the interviews, the mothers' comments indicate that arriving to start the speech therapy is the beginning of a process that takes place gradually according to what they feel and how they perceive the involvement between the health care professional, the child and the family[22]. They observe and interpret attitudes that lead to the construction, deconstruction and reconstruction of images and behaviors. Analysis of their comments suggests that it is during this process that the mothers experience a feeling of reception or not. It is at these times that decisions are taken and impressions gained that determine whether the treatment will be continued or not[23].

The difference reported by mothers in the way that the service is provided is linked to the way each health care professional views clinical practice. This finding corroborates research on how the therapeutic space is used and how the health care professional understands clinical practice[24], both of which factors are present in speech therapists' practices.

If the clinical space is thought of as a way of potentiating transformations related to the family's request for help, then it is possible to think about the difficulty in question. Here it is worth recalling clinical practice based on subjectivity, which seeks to understand the individual and his context[6] in order to help him recover.

The users' comments show that they recognize the speech therapist as the health care professional who will care for/treat people's speech[25]. Arriving at the outpatient unit where children with speech difficulties were seen was therefore not a source of discomfort for the mothers as they understood the speech difficulties associated with communication [26]. However, it could be seen that they were not familiar with the particularities of speech therapy.

The fact that the mothers were already attending the hospital and that their children had been seen in other outpatient units may explain their surprise at the continuous nature of the speech therapy, unlike what they were used to when their children were seen by a doctor during an initial visit and

on subsequent prearranged return visits with long intervals between them. This is reflected in I1's comments: "I could see that it was different. I would never have imagined it was like that. It was treatment rather than a visit to the doctor." [...] Then I started to see things differently."

It is worth stressing that speech therapy practice has a dynamic structure with well-defined, interconnected stages (interviews, assessments and treatment) to enable the speech therapist to learn about the patient, his family and their circumstances[27].

It can be seen from the reports that constant observation, together with interpretation of what the family sees and feels, is fundamental to develop a closer relationship with the family, leading to the conclusion based on the family's comments that the development of a bond with the family and the stimulus to continue with and participate in the treatment starts with the way the child acts. The very clear changes the child undergoes are proof for the family of the safety offered by the speech therapy outpatient unit and the trust they put in the meetings with the health care professionals that work there.

"He's different when he comes here. He doesn't look like he's coming to hospital for treatment. Also because it's a question of trust," I6 emphasized when she spoke about her son's behavior.

It is has been shown that bonding only develops if the user is recognized as a subject who talks, judges and has wishes[18]. Hence, a strong bond can only be established if there is trust, friendship and mutual respect, providing the safety needed to open a channel for exchanges. The health care professional's practice begins to share and be complemented by the family's knowledge as the parent accompanying the child starts to feel important and able to participate and see the consequences of his or her acts.

In the parents' comments, the conversations held as part of the speech therapy are highlighted as important moments when those involved come closer together because they allow knowledge to be exchanged, not as a way of teaching but as an opportunity for learning about each other[28]. By learning about the family, the speech therapist can observe the influences and traditions transmitted by previous generations[29], thereby helping to understand certain attitudes[30].

It is important for speech therapists to understand the user, their family and their environment[31]. It is their responsibility to create opportunities for the family and child to get closer to them and learn about their work, opening up a space for dialog without domination or submission.

Dialog means communication and intercommunication. It is a horizontal relation between A and B[32], "and I always found that positive, the conversation", as I6 stated.

The comments show that listening is much more important than speaking; nonetheless, health care professionals are more used to the latter. Closeness to the family provides a more open, spontaneous dialog and creates opportunities for constructing a space for reflections and interpretations based on the combined knowledge of those involved. It is in this process of interaction and coexistence that the different modes of care take place[33]. This is confirmed by I1's comments: "To be honest, the treatment was good for me as well as for him. [...] I started to see things differently."

It is important to remember that "in health the object is not the cure or promoting and protecting health but promoting care, by means of which one believes that the cure and health, the actual goals one wants to achieve, can be reached"[34].

Listening to parents in an environment where therapy is being administered creates a space for reflecting on and resignifying practices[35]. The interview responses showed that the conversations and exchanges produced positive silent changes in participants' self-confidence and self-esteem. This is related to empowering, which is taken to mean a change in mentality as a result of the subject's perceiving his own strengths, leading to self-confident behavior[36], as in the case of I4: "Now I know what is important for him."

It can also be seen that greater closeness and family participation allow the more important elements of the rehabilitation process to be identified, reinforcing important actions that should be continued. When they are working with families, speech therapists should reflect daily on their practice because each family not only has its own particularities, but also undergoes transformations according to what its needs are and where it is in the life cycle. It is therefore the responsibility of health care professionals to develop practices and actions that stimulate greater closeness and trust in the care process.

CONCLUSION

Understanding families' contexts, habits, customs and moral values is of fundamental importance as these determine a family's standards and how its members develop. A knowledge of this conjuncture helps to understand the mechanisms in the family group and allows the health care professional to gain an insight into the best way of working with a family. However, this knowledge can

only be acquired if opportunities for bringing families closer to the health care professional are created by affording them the respect and reception that are essential to the care process.

The greater the closeness and trust in the relationship between the health care professional and the family, the greater will be the chances of delivering treatment successfully. As this closeness will create opportunities for listening to and learning about patients, there will also be an opportunity for the health care professional to constantly reassess his practice and make any necessary adjustments to achieve the intended goal.

RESUMO

Objetivo: compreender a percepção da família em relação ao atendimento ambulatorial fonoaudiológico. **Métodos:** foi realizada entrevista semiestruturada com seis mães de crianças em atendimento no ambulatório de fonoaudiologia de um hospital público de Curitiba-Paraná. Foram adotados três critérios de inclusão das participantes: tempo superior a cinco meses de tratamento fonoaudiológico, comparecimento semanal e disponibilidade para participar da pesquisa. O método utilizado para o tratamento dos dados obtidos foi a análise temática, identificando-se, na categoria "atendimento", as seguintes subcategorias: reconhecendo o serviço, vínculo e práticas. **Resultados:** constatou-se pouco conhecimento familiar sobre a terapia fonoaudiológica, fragilidade das famílias, necessidade de um processo de vinculação com as famílias e reconhecimento das práticas por elas desenvolvidas. **Conclusão:** o respeito às singularidades de cada grupo familiar favorece a interação da família com o profissional e o enriquecimento do processo terapêutico, permitindo o desenvolvimento da autoconfiança e da criação do vínculo, essenciais para a participação familiar nesse processo.

DESCRITORES: Família; Fonoaudiologia; /terapia; Humanização da Assistência.

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