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THE COMPREHENSIVE EVALUATION IN SPEECH THERAPY FOR PEOPLE WITH VISUAL IMPAIRMENTS: A CASE REPORT

A atuação fonoaudiológica no acompanhamento integral da pessoa com deficiência visual: um relato de caso

Ana Cláudia Fernandes ⁽¹⁾, Rita de Cassia Ietto Montilha ⁽¹⁾

ABSTRACT

Speech therapy as a science aims to study and favors the communication of the subject with their social groups, including: the family. The participation of this speech pathologist is essential in the therapy team working with visual impairment. Thus, the integrated work between professional and family becomes of great theoretical and practical relevance for rehabilitation. The objective was to conduct group intervention with relatives in order to promote knowledge about visual impairment, enable and qualify their conduct in the inclusion process. The study was conducted in a university rehabilitation service. It was obtained approval of the Ethics Committee and the participants signed an informed consent form. Data collection occurred through initial and final interview and group intervention with family and focus groups with teens. The initial interview supported the selection of topics for group meetings. This paper reports the case of a family member who implemented changes in his home, taking the information from the intervention groups to the whole family. The results highlight the importance of working with the family so that it supports the child in order to promote their school development and effective inclusion. It was showed the importance of the speech therapy work as a mediator in this process, enhancing communication and family involvement in education and rehabilitation of persons with visual disabilities. Therefore, the group intervention enabled and described the conduct of the family, been able to notice changes in perception and family attitudes towards real needs and possibilities of the child with visual impairment.

KEYWORDS: Family Practice; Self-Help Devices; Health of Specific Groups; Speech, Language and Hearing Sciences; Vision Disorders

■ INTRODUCTION

Speech Therapy has a fundamental role in the (re)habilitation of the disabled person, mainly in relation to communication and social interaction. According to Law # 6,965/1981, which establishes the regulation of the Speech Pathologist profession and establishes other provisions, speech therapy acts for the research, prevention, evaluation and speech therapy in the area of oral and written communication, voice and hearing, as well as to improve the speech and voice patterns ¹.

In visual impairment, there are few studies on the role of speech therapy, but it is noteworthy, due to the experience of this study, that speech therapy has much to contribute for this area, since, as referred to by Monteiro², the Speech Pathologist is the professional that works to (re)habilitate communication, thus, his/her work to rehabilitate people with visual impairments is extremely important, since subjects need different ways to communicate, favoring their effectiveness and enabling social interactions ².

Decree number 3,128/2008, which establishes that State Care Facilities for People with Visual Impairments are constituted by basic care actions and Visual Rehabilitation Services, on art. 1, paragraph 2, considers as low vision when the visual acuity value corrected on the best eye is lower than

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0.3 and higher than or equal to 0.05, or the visual field is lower than 20° on the best eye with the best optical correction, and considers as blindness when these values are below 0.05 or the visual field is lower than 10°³.

These are important data to evaluate and choose the best way to (re)habilitate people with visual impairments; there are several assistive technology resources for visual impairments, and they may have a low or high cost, which, according to Gasparetto, Maia, Manzini, Maior, Nascimento, Miranda et al.⁴ encompass not only products, but resources, strategies and practices that promote the functionality of the person with visual impairments during his/her activities. It is worthy to highlight the importance of working with the family, which may contribute for these practices, aiming at autonomy, independence, quality of life and inclusion.

According to Rodrigues⁵, inclusion is an ongoing process that must become a reality, but for it to be practiced, the individual differences must be accepted, valorizing the potentialities of each one.

Therefore, for the full development of the visually impaired person, it is fundamental that the family is informed and oriented as to the actual conditions of the child, in order to understand and favor his/her potentialities. The family has a facilitating role for the acquisition of the posture and movement patterns, education, learning and intelligence, and, mainly, for the construction of the personality of the subject⁵.

One of the strategies used in the rehabilitation process on the rehabilitation service of the university, where this study was developed, is the family group. This space allows them to reflect on feelings and to share them with other family members; in addition, it is an environment of profound knowledge and to acquire information that are shared with the other members of the group. The group promotes communication and social interaction, reducing the isolation and suffering of the person⁶.

Therefore, the objective of this paper was to conduct a group intervention with the family members of teens with visual impairments, in order to promote the knowledge on visual impairment, enable and qualify their behavior in the inclusion process.

■ CASE PRESENTATION

The case is part of a broader research entitled "The participation of parents and/or care-takers in the development of students with visual impairments" financed by a governmental institution and that is connected to the study "*Students with visual impairment: perceptions as to their schooling process*", which was submitted and approved by the

Research Ethics Committee (CEP) – of UNICAMP, under number 486/2009, CAAE: 0392.0.146.000-09.

The participants signed the Free and Clear Consent Term (TCLE) for Parents; and the TCLE for Teens, since the subjects were both the parents and children who were under the care of the rehabilitation service of a university. The inclusion criteria for the subjects in the research were: visually impaired teens, under the care of the referred service and parents and/or care-takers of visually impaired teens participating in at least four groups of parents during the studied period. Family members of children and adults and family members of teens that did not participate in or that left the family groups were excluded.

The names represented here are fictional, with the purpose of preserving the identity of the research subjects as follows:

- Diego (child), 18 years old, student from the 2nd grade of the Secondary School of a state school from a municipality in the inner part of the State of São Paulo, with an Ophthalmologic Diagnosis of visual loss due to a tumor (Frontal Lobe Parameningeal Rhabdomyosarcoma) and Diagnosis of subnormal vision (low vision) since 16 years old.
- Wilson (father), 47 years old, was the family member who participated the most in the family groups (7 out of the 8 conducted).

For the study, the longitudinal qualitative method was chosen, since this is a broad methodology that reflects about social aspects, trying to know and analyze aspects of society, that is, of the collective, not through quantitative means. It answers to very particular questions, since it Works with the universe of meanings, reasons, aspirations, beliefs, values and attitudes⁷.

*"The qualitative research answers to very particular questions. It is concerned, in social sciences, with a level of reality that may not be quantified. That is, it works with the universe of meanings, reasons, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relations, processes and phenomena that may not be reduced to the operationalization of variables"*⁸.

The data collection began with an open interview with the father, and the participant had the opportunity to answer to the questions openly. The analysis of the initial interviews was the subside to choose the themes for the group intervention, which were recorded in video and as a field journal. After the group meetings, a last interview was conducted

in order to verify any changes in the role of the father regarding the demands from his son, after the group intervention. A focus group was also conducted with the teens, in which they had the opportunity to report whether there were any changes to the behavior of the family members after the participation in the group meetings.

The study of this case involved the dialectical analysis of data, through the speeches collected in interviews, since “science is built on a dynamic relationship between the reason of those who practice it and the experience that comes from concrete reality”⁸. This statement highlights that the qualitative research occurs through an approximation of the reality experienced by the collectiveness, and, therefore, it must be integrated to the social context of the studied theme.

These different stages of data collection contributed for the analysis of the content, which is characterized by a broad and detailed study with an empirical origin, which tries to understand the phenomena within their context. Minayo⁷ describes that this type of analysis consists in finding out the “cores of meaning” contained in the communications,

whose presence or frequency has some meaning. Regarding the content analysis, Bardin⁹ says it is:

“(...) a set of techniques to analyze the communications with the purpose of obtaining, through systematic and objective description procedures of the content of the messages, indicators (whether or not quantitative ones) that allow the inference of understandings related to the production/reception conditions (inferred variables) of these messages”⁹.

The family groups occurred biweekly, and eight meetings were conducted in which the themes were based on the use of low cost and high cost assistive technologies, allowing parents to get to know and discuss with their peers which were the ways to promote the development of their visually impaired children through reading and writing resources, games and activities in the daily life. Considering this, the testimonials described in the results were given (Figure 1).



Figure 1 – Resources used during the group meetings and visual impairment simulators

■ RESULTS

The dynamics intended with the study favored the inclusion of these teens in the family, at school and in the society, since the family had the opportunity to put itself in the shoes of the children and experience, through simulating glasses, the experience of having a disability.

The low vision and blindness simulating glasses were very important in order for Mr. Wilson to be able to think about his role on the life of his son and, in addition, for him to experience the difficulties and to have the opportunity to think about how to make it easier for his son to have greater autonomy.

During the initial interview, before the group intervention, Mr. Wilson said the following:

- On his expectations in relation to the future of his son:

“we expect... it depends on him... he () wants to have a degree in something... (...) ... we tell him... we are here to support you... I hope... this will be interesting for your future... we tell him to be interested... ()... to study there even harder. (...) He says he wants to have a degree in something... but he doesn't know what yet... before, he said he wanted to be a civil engineer... but then he lost his vision... now... let's see what he does...” (Wilson)

- On the autonomy of his son:

“(...) I fear for him at home and when he goes out... He is afraid to go out... He is afraid to take things at home...” (Wilson)

Initially, it was suggested that the father, during the group intervention, used the simulating glasses to perform a craft activity, and the father was able to realize how difficult it was, however, but even harder for him than the task was the feeling that this first direct contact with the impairment of his son brought to him:

“(...) it was hard for me to put on this thing over my eyes... these glasses... and seeing how hard it is... (...) I felt a little down... I was touched to know what a son of mine is going through (...)” (Wilson)

On the other groups, the themes diverged between activities and assistive technology resources that could be used to conduct the school tasks, in addition to resources for the daily life activities, aiming at all times at the autonomy of

the teenager and the family as a facilitator of this process.

Diego studied on a state school of a municipality in the inner part of the state of São Paulo, with other visually impaired students on a regular class. The school was emphatically involved with the visual impairment, trying to, through the educational system, request all feasible resources according to the needs of the adolescent, as mentioned by his father:

“(...) there is one material they gave him... so one is at home and the other is at school... so when he is at home he studies what is at home... and when he goes to school, he studies with the one at school...” (Wilson)

During the daily life activities, also wearing the simulating glasses, the father cooked and came up with strategies on how to use the kitchen or how to differentiate the shampoo from the conditioner, or even how to favor the contrast regarding the tooth paste; the father came up with possibilities to favor the autonomy of his son at home:

“(...) how to teach him... for example... how to teach him how to do things at home... in the kitchen... to organize things... on the right place...now we leave all the bowls in the right place for him to get... even in his closet... on the bottom, we put the shows, then they are not on the ground anymore... he already knows where they are... he goes there... opens the closet and he already knows where they are... we have already oriented him... it was a good thing that I learned here... I didn't know... we left everything all over the place... you know? ... so when he needed something, he asked someone to get for him... now it's different... now everything is organized... so it was something good I learned...” (Wilson)

And the family group allowed the family to get to know its role and develop its capacity to demand their rights and to have the necessary knowledge for an adequate performance of their children in their activities. The group is rich in feelings expectations and knowledge.

“this group I was part of was important for me...” (Wilson)

“oh... a lot has changed... i have changed a lot, you know?... many things I didn't know... with him I learned... mainly to be more patient, you know (...)” (Wilson)

Such achievement is seen when the autonomy aspect is considered:

"(...) everything... he was afraid of everything, for example, being in the kitchen... because he couldn't find things... then, we organized everything so he could use things... it was really interesting... because now he does it himself... he even cooks by himself..." (Wilson)

"(...) finding things with those glasses is hard... because you have to get near... that's why it's hard... so when I got home, I said... look, son... so we're having a scale of cans here... in the small one, we have (...) the other one is for coffee... the other one will have... things are all in the right place... in the last one, which is the large one, is the rice... now, if you want to prepare some food, you already know... then he gets things... I installed an automatic stove, then it's easier for him to turn it on... he makes coffee... rice... he can also prepare anything" (Wilson)

"he is even going out by himself... now he goes out by himself... () I don't know if I told you he was afraid of going out by himself on the street... now he goes out too much..." (Wilson)

"he does... he has references... and now he already knows... he already knows the streets and everything... because he goes out... and then... today we were coming here by bus and he was showing me places I didn't even know. (...) he is not afraid anymore" (Wilson)

As described above, major achievements were seen favoring Diego due to the mobilization of his father from the group intervention oriented toward the family, which, as may be noticed, promoted the perspective of the family toward the potentialities and possibilities of the visually impaired adolescent.

However, it is important to consider all the feelings involved in this relationship that intermediates the communication between father and son, as seen in the testimonial by the teenager:

"(...) He saw the hard times we have... At least my father did... He is doing things... Really to help me out... To empower me... (...) Like... Putting food on my plate..." (Diego)

For the therapeutic process and for the family relationship, it is important for professionals to pay

attention to these data, showing the ambivalences involved in social relations, mainly those concerning the family relations when a child has some kind of disability, after all, on the testimonials by Mr. Wilson, we noticed on his speech the desire for his son to have autonomy and independence, however, as he son shares, he still puts food on the plate of his son, a routinely action, but which may also show considerable care toward his son.

■ DISCUSSION

Working with the family is essential for the work of speech therapy and the areas of health and education in visual impairment, since it is the first social group of the impaired person, and the beginning of the communication and relationship toward others.

*"The family is a source of protection and psycho-social care of its members, and it is also an important unit to transmit the culture throughout the generations. It needs to be understood as a group with rules, myths, standards and styles of communication, connections and intense emotional bonds, roles and hierarchies"*¹⁰.

Defendi, Sanchez, Araldi and Mariani¹⁰ mention that the family goes through a unique time when they find out about the disability of the child, involving feelings of rebellion, discomfort, anxiousness, fear, shame, weakness and guilt, but it is necessary to consider that these feelings are not "wrong", they are part of a time that must be respected. This is where speech therapy has an important role, trying to, together with the psychological support whenever necessary, empower the family to recover communication, interaction, and reducing the isolation and suffering, since it may be shared with the others on the group who have similar experiences and also with the professionals who are there to listen to and to support them.

*"Family members adapt to the situation and realize that they are not completely powerless, and that there is still much to be made in order for this person to develop his/her potentials, no longer highlighting only the limitation of the disability"*¹⁰.

It is important for the professionals in the area of health and rehabilitation to act together with the family, because, when there is a connection with it and it is sensitive to the issues related to the care needed by the impaired person and when it

understands the potentialities of this person, we may notice that the professional becomes only a mediator of the rehabilitation process, providing tools to the family, in order for it to create its own strategies and follow its own path with autonomy and safety.

Therefore, the findings by Chiari, Bragatto, Nishihata, and Carvalho are noteworthy ¹¹:

“After the diagnosis (...), there is damage to the Family dynamics, making the person with disabilities unproductive, retracted and repressed. The expressivity regarding spontaneity, emotions and desires is directly affected. The social exclusion of the individual is promoted, restricting the circle of friends of this person to the family members” ¹¹.

This may be noticed when Mr. Wilson reports the changes conducted at his home that changed the dynamics of the family, such as the organization of the room of his son, and the kitchen, in an attempt by all family members to keep the house in the same manner at all times in order for Diego to have more autonomy in the environment.

When Mr. Wilson says “he is not afraid anymore”, we need look at both sides. The son is no longer afraid, because the father is also no longer afraid. He felt safe and got to know the possibilities his son has, promoting them. This all happened not because he participated in discussion in the family group, but because he used the tools that were given to him ¹⁰.

In the study by Andrade-Figueiredo, Chiari, Goulart ¹² discussed such finding, which is in agreement with what is discussed here, in which the visual impairment may create feelings of insecurity for the autonomy of the person:

“Almost half of the people interviewed thinks that the lack of vision is the most hindering aspect. (...) The visual impairment due to the Usher syndrome causes difficulties to locate objects, for the locomotion and mobility, and the visual rehabilitation and orientation and mobility training are important for a better quality of life” ¹².

It is important that the (re)habilitation and education teams to communicate and create a network to support the family, since it must know how to help the visually impaired children to broaden, create and adapt pedagogical materials, in addition to promote the use of optical resources when necessary and (re)habilitation, in order to favor the use of the visual remains and the autonomy.

Andrade-Figueiredo, Chiari, Goulart ¹², on their work on the communication of deaf and blind subjects add that:

“Knowing the communication abilities and difficulties of deaf and blind individuals may guide public policies to create measures to improve their access to communication and information and, therefore, their independence” ¹².

It is noteworthy that Decree # 3,128/2008 ³, which establishes the care networks for people with disabilities, does not incorporate Speech Pathologists in the minimal care team; however, as it may be noticed on Andrade-Figueiredo, Chiari, Goulart ⁷, speech therapy may have a fundamental role not only regarding hearing issues, but also for the communication and social insertion of the visually impaired person. Therefore, working as a network is so important, including the family as part of this care, since it is with the participation of the population and of the health, (re)habilitation and education professionals that the care policies may be recreated.

The intervention groups with parents showed that only the technological equipment and resources do not assure the effectiveness of the suggested objectives, but that the problem among the assistive technology resources, Independence and autonomy, inclusion and social exclusion – considering that these themes are inter-related – favors the acceptance of using the resource not only by the family, but mainly by the visually impaired person, since this person will feel accepted ¹³⁻¹⁶.

Therefore, it is noteworthy the interest of this father who tried to apply at home so many changes to favor his son, and despite his great participation in the groups and the suggested activities, it is important that the entire team is open to listen to the child and to understand the real feelings that are related under these circumstances.

As described in the results, the son realizes the changes made by the father, but he also realizes the important of the participation of his father in the intervention groups, however, an ambivalent feeling is still present, and it must be respected and understood by the team, that the father needs to stay near his son, such as when he “puts food on the plate”; this attitude, in terms of autonomy, is not a facilitator, however, when the professional is open to understand this relationship, he sees how emotional is the testimonial of the son and how much the father still experiences the ambivalences of this relationship, which is completely natural in cases of families with

children with disabilities, mainly when the disability is acquired throughout life, as in this case.

The results shown in this study confirm the principles of the Health Ministry, considering the adaptations for routine activities and structural adaptations in household environments as elements that allow the compensation of the functional and sensorial limitations, allowing the family and the visually impaired teenager to overcome the barriers involved in communication and mobility in order to enable the full social inclusion of the visually impaired teenager within the family, at school, in the society and all social groups that surround this person ¹³.

In order to confirm the findings of this study and the role of speech therapy in the visual impairment, it is worthy to highlight once again the statement by Chiari, Bragatto, Nishihata, Carvalho ¹¹:

“(...) Speech Therapy may collaborate for the important identification together with the patients of their communication needs and priorities, establishing realistic goals that would effectively reduce their handicaps and, consequently, provide better quality of life” ¹¹.

■ CONCLUSION

The perception of the father changed after the group intervention, because he did not know about the resources that could be used with this son and he also had not had the opportunity to simulate a visual impairment and experience the difficulties of the disability.

Therefore, we observed that the group meetings with the Family members promoted the necessary understanding for the family to feel safe to adopt new behaviors.

In addition, we observed that the father in the studied case then understood the real needs and possibilities of his son, taking to the entire family he knowledge acquired, changing the family dynamics and (re)organizing the house to favor the visually impaired child, in order to promote his autonomy.

It was possible to notice that when at least one of the family members is supported and oriented by the therapeutic team, the information allow and qualify the search for an effective inclusion of the visually impaired person at school, within the family and in the society.

RESUMO

A Fonoaudiologia enquanto ciência visa estudar e favorecer a comunicação do sujeito com seus grupos sociais, entre eles: a família. Considera-se fundamental a participação do fonoaudiólogo na equipe terapêutica que atua na deficiência visual. Sendo assim, o trabalho integrado entre profissionais e família se torna de grande relevância teórica e prática para a reabilitação. Objetivou-se realizar intervenção grupal junto aos familiares a fim de promover conhecimento sobre deficiência visual, viabilizar e qualificar sua conduta no processo de inclusão. O estudo foi realizado em um serviço de reabilitação universitário. Obteve-se aprovação do Comitê de ética e os participantes assinaram o TCLE. A coleta de dados ocorreu por meio de entrevista inicial e final, além de intervenção grupal com a família e grupo focal com os adolescentes. A entrevista inicial subsidiou a seleção dos temas para os encontros grupais. Este trabalho relata o caso de um familiar que implantou mudanças em sua casa, levando as informações dos grupos de intervenção a toda família. Os resultados destacam a importância do trabalho com a família para que ela ofereça suporte ao filho a fim de favorecer seu desenvolvimento escolar e efetiva inclusão. Evidenciou-se a importância do trabalho da Fonoaudiologia como mediador desse processo, valorizando a comunicação e a participação da família na educação e reabilitação da pessoa com deficiência visual. Portanto, a intervenção grupal viabilizou e qualificou a conduta dos familiares, sendo possível notar mudanças na percepção e atitudes da família em relação às reais necessidades e possibilidades do filho com deficiência visual.

DESCRIPTORIOS: Prática de Família; Equipamentos de Autoajuda; Saúde de Grupos Específicos; Fonoaudiologia; Transtornos da Visão

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