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Interaction between family and child/adolescent with hearing deficiency

Interação entre a família e a criança/adolescente com deficiência auditiva

Keywords

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 Child
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 Caregivers
 Health Care

Palavras-chave

Deficiência auditiva
 Criança
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 Cuidadores
 Atenção à Saúde

ABSTRACT

Purpose: to know the family interaction with the hearing impaired child/adolescent. **Methods:** descriptive and exploratory qualitative research developed at a Special School in Southern Brazil. Participants were 10 primary caregivers of deaf children/adolescents between 10 and 19 years old. The collection took place in November 2017, through semi-structured interviews containing questions about the communication process of deaf children/adolescents with their families. The information was analyzed through thematic analysis. The study was submitted and approved by the Ethics Committee under opinion number 2.333.560. **Results:** as the main theme of the study “Interaction between the family and the child/adolescent with hearing impairment”, it addresses two sub-themes: potentialities and weaknesses in the communication of the family with the child/adolescent with hearing impairment and learning in the care of the child/adolescent with hearing impairment. **Conclusion:** it was identified that the interaction of the deaf with the family and society is impaired by people’s lack of knowledge about the deaf community and the Brazilian Sign Language, which raises concern in caregivers who often overprotect the child/adolescent which may limit the full development of their skills and autonomy.

RESUMO

Objetivo: conhecer como ocorre a interação da família com a criança/adolescente com deficiência auditiva. **Método:** pesquisa qualitativa de caráter descritivo e exploratório desenvolvida em uma escola especial no Sul do Brasil. Os participantes foram 10 cuidadores principais de crianças/adolescentes surdas entre 10 e 19 anos. A coleta ocorreu no mês de novembro de 2017, por meio de entrevista semiestruturada contendo questões acerca do processo de comunicação de crianças/adolescentes surdos com suas famílias. As informações foram analisadas por meio de análise temática. O estudo foi encaminhado e aprovado pelo Comitê de Ética sob o parecer número 2.333.560. **Resultados:** desvelou-se como temática principal do estudo “Interação entre a família e a criança/adolescente com deficiência auditiva”, que contempla dois subtemas: potencialidades e fragilidades na comunicação da família com a criança/adolescente com deficiência auditiva e aprendendo no cuidado da criança/adolescente com deficiência auditiva. **Conclusão:** identificou-se que a interação do surdo com a família e a sociedade é prejudicada pelo desconhecimento das pessoas acerca da comunidade surda e da Língua Brasileira de Sinais, o que gera preocupação nos cuidadores que, muitas vezes, superprotegem a criança/adolescente, podendo limitar o pleno desenvolvimento de suas habilidades e autonomia.

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INTRODUCTION

The family is an important place of relationships, because through family members and their exchanges that the child builds his/her identity. Thus, the family environment may or not, depending on the quality of their relationships, build an appropriate psychic and linguistic development for the child⁽¹⁾.

Under these circumstances, social relationships and dialogues established by the family are essential for the child's development. By facing these interactions the child inserts himself/herself in the family communicative universe, developing his/her linguistic knowledge more and more⁽²⁾.

Hearing impairment is characterized by the difficulty or impediment of the individual to hear the background noise, whose electrical stimuli do not reach the brain. In addition, the hearing impaired child may experience delay or change in speech. Hearing impairment may be present at the childbirth or may be developed in the postpartum period or throughout life, due to some comorbidity⁽³⁾.

In this context, the diagnosis of hearing impairment can be seen through a strong impact on the family, transforming family relationships, while disorder, conflicts and difficulties may occur due to possible communication problems among its members, requiring the participation of the entire family nucleus in the process of adaptation¹. Furthermore, with the diagnosis of the child's hearing impairment problem, there is a transformation in the family relationship, in which the parents start to feel sorry for the child, sadness, guilt and helplessness, discomfort in the games, disappointment, among other feelings, while they go through the process of becoming aware of the situation lived at the time reflected⁽⁴⁾.

Considering that the family environment represents the space in which the child/adolescent has his/her first experiences of interpersonal relationships, the family play an important role of positively boosting the construction of the personality of the deaf as people with autonomy and capacity to perform any activity. In this sense, the parents' view during the child's growth is extremely important in the way that deaf children will later perceive themselves in their individuality^(5,6). Because the family's perspective in relation to the child's image directly influences the way the child will perceive himself/herself in the world, that is, it influences the child's perspective of his/her identity⁽⁷⁾.

The same occurs in the adolescence phase, and communication difficulties can evolve into troubled interactions, representing a confused reference for the developing teenager. Deaf adolescents with hearing parents have a "greater break" with the family group after keeping in touch with the deaf community, as they see the possibility of reaching uniqueness, feeling more belonging to the affinity group than to the family⁽⁵⁾.

To be a hearing impaired child/adolescent is a complex challenge, as communication difficulties can impair socialization and, consequently, all other areas that involve social relationships, which can lead to withdrawal from social activities and can contribute to insecurity and the child/adolescent may be exposed to situations of greater vulnerability when compared to individuals without this deficiency⁽⁸⁾.

At this juncture, it is necessary to take extra care with deaf children and adolescents, as their dimensions of vulnerability are increased, which often compromises their relationships in the family and social environment. Therefore, in your care, these particularities must be respected⁽⁵⁾.

Based on the subjects described above, the importance of communication is identified for the interaction of the family and society with the hearing impaired child/adolescent. However, there are many gaps related to the limited scientific production on the subject, with a greater focus on the development of oral and written communication of the population with hearing impairment^(9,10), compared to the listening population^(11,12), than in the interaction of this population with their families and society. As could be seen, this study aimed to understand the interaction of the family with the hearing impaired child/adolescent.

METHODS

This is a qualitative research carried out in a special school for the deaf in a municipality in southern Brazil. This school is a philanthropic institution, which contributes to the bilingual education of students who have various levels of deafness.

Data collection took place in November 2017, through a semi-structured interview, containing questions about the communication process of deaf children / adolescents with their families (data were collected on the caregiver's characterization such as: degree of kinship, age, education and profession. For the child/adolescent: data on age, sex and degree of deafness were collected, and an open question was proposed for the caregiving participants to describe how the child / adolescent communicates within the family environment). This collection took place in the space of the school in question, in a private environment, individually. The interviews were recorded on a cell phone and manually transcribed, with an average duration of 50 minutes.

The number of participants was not predetermined, and the interviews were carried out until the information was saturated. For that, firstly, the interviews were transcribed, extracting the initial codes. After this stage, the codes were categorized by prevalence and type, so it was identified that each code obtained sufficient depth and complexity to understand the question studied⁽¹³⁾. Therefore, in this study, saturation was achieved with 10 interviews, understanding that the data provided sufficient depth and complexity to understand the phenomenon of interest.

Thus, 10 main caregivers of hearing impaired children/adolescents, who attended the study institution, participated in the study. It was used as an inclusion criterion to be the main caregiver of a hearing impaired child/adolescent who attended the school. Caregivers who had no verbal communication were excluded.

The data were analyzed through thematic analysis, following six steps: familiarization with the data, from the reading and re-reading of the data, the basic structure of the information is composed; generation of initial codes; searches for themes, grouping the relevant coded data extracts in each identified theme; review of the themes, selecting the most relevant ones;

definition and naming of themes; and the final analysis and production of the report relating the content of the themes to the literature⁽¹⁴⁾.

The organization of the data for analysis was done manually and checked by two reviewers, aiming to validate the themes that emerged from the interpretation of the information. The central theme unveiled in the study “Interaction between the family and the child/adolescent with hearing impairment” unfolded into two sub-themes: strengths and weaknesses in the family’s communication with the child/adolescent with hearing impairment; learning in care of the hearing impaired child / adolescent. In order to arrive at the selection of this theme and its subthemes, an in-depth reading of the participants’ reports was carried out, first selecting the codes related to the family’s interaction with the hearing impaired child/adolescent. Subsequently, the statements related to the potentialities and weaknesses experienced in communication were separated and, later, those related to the care of the child/adolescent with hearing impairment.

All ethical guidelines for research with human beings were respected, and the study was forwarded and approved by the Ethics Committee under opinion number 2,333,560 before collection⁽¹⁵⁾. Also to meet these precepts, the participants signed the Free and Informed Consent Form, by which they agreed to voluntarily participate in the study. The anonymity of the interviewees was maintained, naming them by the consonant “C” (caregiver) followed by a sequential number (C1, C2, C3 ...).

RESULTS

The 10 main caregivers of children/adolescents with hearing impairment who participated in the study were mothers. Most of these mothers had incomplete high school education, with three participants having completed high school. Regarding the profession, eight reported being “stay-at-home mothers”, one reported being a merchant and a student.

With regard to children and adolescents, they were in the age group of 10 to 16 years old, six male and four female. All have a severe/profound degree of deafness and two make use of technologies that assist them in the perception of hearing.

It was unveiled as the main theme of the study “Interaction between the family and the child/adolescent with hearing impairment”, contemplating two sub-themes: strengths and weaknesses in the communication of the family with the child/adolescent with hearing impairment; learning in the care of the hearing impaired child/adolescent.

Interaction between the family and the hearing impaired child / adolescent

The interaction of the family with a hearing impaired child/adolescent is experienced in different ways, with potential and weaknesses arising in this context, which are related to the way that communication occurs between family members and between them and society. In addition, the birth of a hearing impaired child imposes on the family the need to organize itself

to meet the demands, confronting the “idealized child” with the “real child”. So, in the care of the hearing impaired child/adolescent, the family learns new ways to face their reality.

Potentialities and weaknesses in family communication with the hearing impaired child / adolescent

Communication is considered an essential tool for interaction between people, so when it does not occur effectively it weakens family relationships. In this context, the research participants report that they seek to invest in the qualification of communication seeking new knowledge about communication with signals to better understand the needs of their children, as can be seen in the statements:

Every time there was a sign language lesson here, I did it too, even if I had already done it I did it again [...]. [...] because it has to be always updating, because the signal changes sometimes (C1).

She communicates more in Sign Language with me and her sister. [...] We both took a course (C4).

His brother is learning (C9).

The search for knowledge of the language of SIGN LANGUAGE has been a concern of the participants, since they understand the need for it to communicate with their children.

Because I want to learn, I want to talk like him, I want to know what's going on with him (C1).

Since I started here at school, I am taking courses. I didn't even do all of them, I did the basic and intermediate because the advanced courses are not full. [...] I lack a lot of communication with him, because he is growing and it is getting more difficult, he asks more complex questions, but we are leading (C10).

To consider deafness in the context of childhood and adolescence represents a significant change in this process, since, at that moment, it will be perceived by its limits. However, family members do not always invest in qualifying communication with the hearing impaired child / adolescent, as can be seen in the following reports:

He also has difficulties with his own family. Some part, not all, but some have difficulty signaling with it (C3). His father does not know how to communicate with him (C5).

Only SIGN LANGUAGE is my course, the rest [of the family] is with the day to day (C6).

She [grandmother] usually talks to him, but it is useless to talk because he does not listen (C7).

When the father wants to talk to her, I signal to her that the father is speaking and so I stay with them (C8).

The family members’ difficulty in communicating with the hearing impaired child/adolescent, added to the fact that they have no communication alternatives to the spoken language, creates an overload for the main caregiver who has learned to communicate with the language of SIGN LANGUAGE.

The dynamic is “me” for everything, I have to be with him directly for everything, everything, everything (C10).

To be deaf with hearing parents generates an impact of cultures, especially language, considerably decreasing communication between parents and children. However, the existing conflict due to the stigma of deafness, unpreparedness and difficulty in acceptance can lead to the dissolution of the family.

There was another [deaf child] that her mother was a teacher and died [...] and then the father put her up for adoption because he didn't understand her, well, difficult (C1).

This moment of emotional fragility can generate many internal and external conflicts, making the separation of parents facing a differential diagnosis a reality faced by many families.

Learning in the care of the hearing impaired child / adolescent

With the birth of a son with hearing loss, the family goes through an adaptation process, experiencing the confrontation of the “idealized son” with the “real son”.

His great-grandmother looked at him and said “look, I think your son is deaf”, but right..., I didn't know about my first son [...] then his father was also “no, capable” and something I say, I always took him straight to the appointments and the pediatrician said “don't compare your children with others” (C10).

The caregiver's coexistence with the special school environment and with other hearing impaired children and adolescents brings an understanding of the needs they have, favoring acceptance and adaptation to their child's condition:

I learned a lot from them, because it is difficult for you to accept that your son is a child with special needs, it is difficult for you to accept “oh, your son is now deaf”, for me it was difficult. [...] my world started to be different, the coexistence I have with them here and the coexistence I have with my son, for me it is normal, they are all normal (C5).

The need for supervision and greater dependence on parents in childhood and adolescence are increased due to special needs, as they leave children / adolescents more exposed and vulnerable in their actions. However, when children grow up, parents find it difficult to provide autonomy:

They grow up ... [paused to think], because he always wants to come to school alone, but I don't let him, I'm very scared (C2).

Because he is very close to me, even to come here at the school party “everything is me who has to bring him”, “I who have to do things for him” (C7).

For these children/ adolescents to develop their skills and autonomy, it is essential that the family learns to balance the

protective relationship so that it does not exceed the limits and interfere with learning. Furthermore, the participants emphasize that they seek and hope for a more inclusive society, in which the child can be understood, when they are absent:

[...]I also fight for things to improve for him, for him to grow with more confidence, believing that he will improve, someday a good part of people will understand him, that's what I hope (C1).

They grow up and one hour we will not be able to take him to the health center, then he gets there and there is no one who understands them, it is complicated (C5).

I know I will not be with her for the rest of my life, so until the day I die I hope it has improved a lot (C8).

Therefore, the importance that professionals have to face the diagnosis and family planning is highlighted, influencing the way the parents will deal with the situation. In addition, an active family present in the life of the deaf child/adolescent provides security and a sense of belonging, feelings that are fundamental in this period of life, stimulating social interaction and self-confidence.

DISCUSSION

The interaction of individuals with family members will influence the understanding of social relationships, so it is essential that this environment is a place where the child/adolescent feels welcomed, accepted and belonging⁽¹⁶⁾.

This process of subjectivity requires that the child/adolescent may find support and balance, usually coming from the family. This highlights the importance of the family's role in guiding and understanding this individual⁽¹⁶⁾.

It is necessary to emphasize the importance of the family according to the view the child/adolescent will have, as it will be in accordance with the perception of the family that the child will constitute his/her worldview and, consequently, reproduce it as he/she really sees it. Because they understand the importance of the family in the interaction of the adolescent's life, the participants report seeking to learn SIGN LANGUAGE as an attempt to facilitate communication with the deaf teenager.

As a way of minimizing communication barriers, some family members create a dialect within their home environment that facilitates understanding, allowing the children/adolescents to also express themselves. Generally, it is a joint construction to adapt the sign language and the Portuguese language, in order to establish a common communication method that is efficient for all (17), since parents, siblings and/ or the family nucleus will be the most important models powerful and relevant for this child/adolescent⁽⁵⁾.

When it is not possible to establish communication, it is noted that stories, teachings and orientations can be shared, even when the deaf's understanding of their own environment is very limited, making it difficult for them to identify with family members⁽⁵⁾.

There are also situations in which only one family member is responsible for understanding and interpreting the speech of the

child/adolescent for all other family members, creating overload and unilateral responsibility for the care and well-being of that individual. In addition, the deaf child/adolescent who was born in a listening family faces another type of socialization with their parents⁽⁵⁾.

The diagnosis of deafness can generate the most diverse feelings in the parents, for example, denial, guilt, sadness, shock, fear and anguish due to the impact that this new information will bring to the couple's life, which, many times, is not prepared for dealing with those feelings⁽¹⁸⁾.

It is possible to note that the lack of psychological resources and professional support makes it difficult for parents to make decisions and to have emotional stability. It is found that the couple feels lost after receiving the diagnosis, justifying the feelings of fragility and anguish. The preparation of professionals is essential for the family to be able to plan a future in the face of this new context⁽⁴⁾.

Grief is also one of the feelings experienced by the couple due to the projection process of the ideal child that has been built since childhood. This is a necessary step for parents to be able to accept and welcome the arrival of this new child and plan the future from this perspective. The confrontation of the "ideal child" versus the "real one" can cause strangeness, so the importance of mourning for the family to experience the moment of loss of the "ideal child" and for parents to be able to create a healthy bond with the "real child"⁽¹⁹⁾.

However, as the deaf grows and develops, this need decreases. In this context, some caregivers may manifest overprotection, contributing to the feeling of insecurity, incapacity and vulnerability⁽¹⁸⁾. Thus, maximizing opportunities for experience, knowledge and personal and social discovery is a family duty of extreme importance for the child / adolescent⁽²⁰⁾.

Another topic that came up in the interviews was the caregivers' concern for the future. Social inclusion and the desire for their children to be understood by everyone and/or by a large part of people are the main reasons for apprehension of these caregiving mothers.

These fears are also found in parents of people with other types of disabilities due to the fact that this family unit ends up providing a secure base in the face of the difficulties faced by society. In these situations, the professional can provide the host, assist in the understanding of emotions and in the creation of a long-term care system that involves actions that reassure the parents and favor the future of the child/adolescent⁽²¹⁾.

The importance of the health professional for the dissemination of adequate information to parents is emphasized, stimulating the growth and healthy development of the child/adolescent with deafness, in order to modify excessively negative thoughts, reduce the feeling of guilt, assign new meanings to the quality of life and allow the full development of your child's potential.

The study had limitations due to the fact that it was restricted to only one special school and the scarcity of scientific productions that address the deaf child/adolescent. It is suggested that this theme should be addressed in training, bringing more reflections on people with hearing impairment in undergraduate courses in the health area. Furthermore, it is believed that the study contributes to foster discussion based on the theme, both in research and

in assistance, aiming to expand the scope of the importance of the SIGN LANGUAGE language for communication with deaf people, in education and health services, as well as in society in general.

CONCLUSION

The study made it possible to know the family's interaction with the deaf child / adolescent. From the analysis in this study, it was identified that the interaction of the deaf with society is hampered by people's lack of knowledge about the deaf community and the Brazilian Sign Language.

The family becomes essential for the child/adolescent to be understood by other individuals, therefore, the caregivers were the main ones interested in taking SIGN LANGUAGE courses, looking for ways to better understand their children and remain present in the development and in the transition from childhood to adolescence. However, it was also identified that many family members do not have the same understanding about the importance of SIGN LANGUAGE in the communication of the deaf, generating a distance between this child/adolescent and family members and creating a barrier within their own home.

In addition, the family, when faced with the hearing impairment of the child/adolescent, needs to reorganize itself and face the reality of the child/adolescent and its consequences on the child's life and on his/her own. In this context, uncertainties emerge as that of the "so idealized" future that the parents had about the child, and fear haunts them, raising questions about how capable they will be to deal with and help the child/adolescent to face the diagnosis, providing care hearing impairment requires.

Due to the way of dealing with hearing loss, the child/adolescent and his/her family live in situations of vulnerability that arise from the difficulties of daily care, from social contexts, regarding the support networks he/she needs for this continuous care, in addition to the lack actions developed by health services, aimed at promoting growth and development, protecting health and identifying and treating detected problems.

Family members describe the struggle they are experiencing for the inclusion of their children and the excessive protection they exercise, even though they recognize the motivation for their children's independence. In this context, families expect a more inclusive society, prepared to understand the hearing impaired child/adolescent.

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Author contributions

MMT, VMM, RIBG were responsible for preparing the project, collecting the data, outlining the study, executing the project, analyzing the data and preparing the manuscript; VLF and JCV were responsible for preparing the manuscript; study design, guidance and review of the manuscript.