

THE IMPACT OF CEREBRAL PALSY DIAGNOSIS FROM THE PERSPECTIVE OF THE FAMILY

O IMPACTO DO DIAGNÓSTICO DE PARALISIA CEREBRAL NA PERSPECTIVA DA FAMÍLIA

IMPACTO DEL DIAGNÓSTICO DE PARÁLISIS CEREBRAL DESDE LA PERSPECTIVA DE LA FAMILIA

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ABSTRACT

Objective: to learn the reactions of the family when their child is diagnosed with cerebral palsy. **Methodology:** it is a research with a qualitative, exploratory-descriptive approach, developed with 10 participants in the *Associação de Pais e Amigos dos Excepcionais* (APAE) of a city located in the southern part of the State of Rio Grande do Sul. A semi-structured interview and content analysis were used for data collection and interpretation, respectively. The research was approved by the Research Ethics Committee under number 1.992.988. **Results:** the research shows that there is lack of communication between health professionals and families. **Conclusion:** it is essential to create a bond, as well as to open a communication channel between health professionals and family members of the child with cerebral palsy, to assist them from the disclosure and understanding of the diagnosis until the acceptance of the condition to ensure the family's effective care for the child, in order to create social support networks.

Keywords: Diagnosis; Cerebral Palsy; Family Relations; Child Care; Nursing.

RESUMO

Objetivo: conhecer as reações da família à revelação do diagnóstico de paralisia cerebral do filho. **Metodologia:** pesquisa com abordagem qualitativa, exploratório-descritiva, desenvolvida com 10 participantes na Associação de Pais e Amigos dos Excepcionais (APAE) de uma cidade localizada ao sul do estado do Rio Grande do Sul. Para a coleta de dados, utilizou-se a entrevista semiestruturada e para a interpretação, a análise de conteúdo. Obteve-se aprovação pelo Comitê de Ética em pesquisa sob o número 1.992.988. **Resultados:** a pesquisa mostra que há uma falha na comunicação entre os profissionais de saúde e a família. **Conclusão:** é fundamental a criação do vínculo, bem como a comunicação entre os profissionais de saúde e os familiares da criança com paralisia cerebral para auxiliar desde a revelação à compreensão do diagnóstico, até a aceitação da condição para a efetivação do cuidado ofertado pela família à criança, auxiliando na formação de redes sociais de apoio.

Palavras-chave: Diagnóstico; Paralisia Cerebral; Relações Familiares; Cuidado da Criança; Enfermagem.

RESUMEN

Objetivo: conocer la reacción de la familia ante la revelación del diagnóstico de parálisis cerebral del hijo. **Metodología:** investigación de enfoque cualitativo, exploratorio descriptivo, realizada con 10 participantes de la asociación APAE (asociación de padres y amigos de deficientes mentales) de una pequeña ciudad del sur del estado de Rio Grande do Sul. Los datos se recogieron en entrevistas semiestructuradas y se analizaron según su contenido, con la aprobación del comité de ética en investigación bajo el número 1.992.988. **Resultados:** la investigación muestra fallas de comunicación entre los profesionales de salud y la familia. **Conclusión:** es imprescindible crear vínculos y establecer comunicación entre los profesionales de salud y los familiares del niño con parálisis cerebral. De este modo se podría ayudar en la revelación y comprensión del diagnóstico, en la aceptación de la condición, en efectivar los cuidados de la familia al niño y en la formación de redes de apoyo social.

Palabras clave: Diagnóstico; Parálisis Cerebral; Relaciones Familiares; Cuidado del Niño; Enfermería.

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INTRODUCTION

The birth of a child begins before the gestation itself, when parents begin to project and idealize a child. Thus, not only the woman, but the whole family, begins to imagine what the child will be like and who he/she will look like; they imagine the color of his/her eyes, the first word he/she will pronounce and who will give him/her the first bath. The birth of a child is a unique moment, which can cause significant changes in family life.^{1,2}

However, in this idealization, the family does not expect the birth of a child with special needs. And when this happens, family dynamics and relationships may be disrupted. At the moment the family receives the diagnosis of cerebral palsy, the entire family nucleus is affected, which can result in conflicts, fears, insecurities and doubts, as the expectations created during gestation do not correspond to the reality. The family then experiences a process of mourning for the idealized child, who is different from the real one, which can lead parents to despair, since they are usually unfamiliar with the disease, its consequences and treatment.^{3,4}

At that moment, family members go through a phase of shock in which they have difficulty understanding what has happened, and they may feel guilty, added to the feeling of inability to conceive a child within the standards that they had idealized. Faced with the experiences of denial and grieving for the expected baby, the family may have difficulties in creating a bond with the child.⁵ After the repercussion of the diagnosis, there is the confrontation and acceptance about having a child with cerebral palsy, which occurs in a unique way for each family member.⁶ During this process of adaptation, the family begins to analyze its structure and initiates the process of reorganization, as caring for a child with cerebral palsy may require full-time assistance.⁷

The sequelae resulting from cerebral palsy can be minimized with proper and constant stimulation. So, the clearer the diagnosis, the faster the acceptance and the greater the benefits for the development of the child. Therefore, after proper orientation to parents and family members, it is possible that the impact of the diagnosis may be replaced by acceptance and overcoming.^{2,8}

The way the health care team approaches and guides the family is of paramount importance for restructuring this family, as the diagnosis raises many doubts and expectations.^{9,10} The use of scientific language may make it difficult to understand the child's situation and, consequently, the process of adaptation to the child and his/her needs. Therefore, the moment they hear about the diagnosis is a significant one for the families.^{5,11}

In this perspective, it is essential to focus at the family of the child with cerebral palsy, from the moment they hear the diagnosis and throughout the rehabilitation process, in an effort to offer the most appropriate support, using a language easily understood by parents, providing conditions for the clarification of

doubts and fears, enabling the maximum development of their potential.⁴ In this sense, this study aimed to learn the reactions of parents when their child is diagnosed with cerebral palsy.

METHODOLOGY

This is a qualitative research with a descriptive and exploratory design, carried out in the Brazilian *Associação de Pais e Amigos dos Excepcionais* (APAE) of a city located in the southern part of the State of *Rio Grande do Sul* (BR). Data collection was performed between April and May 2017, through a semi-structured individual and private interview at the study site. The participants were nine mothers and one father of children with special needs due to cerebral palsy who attended the institution of the study.

In order to select the participants, the following inclusion criteria were used: to be indicated by APAE's professionals; to be the biological mother or father of a child with cerebral palsy; to attend the institution studied; and to be 18 years old or older. And as exclusion criteria: to be traveling or away from the institution during the period of data collection; parents whose children are not diagnosed with cerebral palsy.

During all stages of the research, the ethical precepts established by Resolution No. 466/12 of the *Conselho Nacional de Saúde* (CNS) of the *Ministério da Saúde* (BR) were followed. Participants' autonomy was ensured through the Free and Informed Consent signed by them and the researcher. In order to preserve the participants' identity, the letters M and P were used for *Mãe* and *Pai* (Mother and Father), respectively, followed by a sequential increasing number that indicated the interview number. The project was approved by the Ethics Committee, under opinion N^o. 1.992.988.

For data analysis, the method described by Minayo was used, which takes place in three phases: pre-analysis, data analysis and data processing.

RESULTS AND DISCUSSION

After analyzing the information provided by the participants, two thematic categories emerged, discussed below:

THE IMPACT OF CEREBRAL PALSY DIAGNOSIS

When talking to the participants about the communication process of cerebral palsy diagnosis, it was possible to notice that there were obstacles in communication between the health professionals and the families regarding clarification of the diagnosis, since family members were not very familiar with the complexity of the disease, as shown in the following statements:

They said she had seizures (M1).

There was lack of oxygen to the brain [...] that is all they said (M8).

Upon analysis of the reports, it is possible to note that, when giving a diagnosis, health professionals used scientific terminologies, which are not understood in common language.¹² Thus, parents did not receive enough information to assimilate the meaning of having cerebral palsy and the complications that it entails.

Failure to understand the diagnosis makes the family feel unprepared to understand their child's health condition. The moment the diagnosis is given to the parents is critical and health professionals are not always prepared to give the news, as they have difficulty understanding the patient's lifestyle, reason why they do not consider it to be a decisive moment in the way how parents will deal with the new reality.¹³

The difficulty in giving a diagnosis and prognosis to the family leads to a delay in the cognitive and physical stimulation of the child with cerebral palsy, considering that the care of this child depends, almost exclusively, on his/her family. When there is no effective communication with the family about the child's diagnosis, there may be a delay in their stimulation, in addition to increasing the difficulties experienced by the family, regarding the acceptance of the child's condition.¹⁴

Informal language can work in favor of the health team, helping to establish a bond with the family, and providing feedback to analyze the level of understanding of the information provided.¹⁵ This procedure is required to evaluate the results obtained and so that health services and actions can be sure of the effectiveness of the guidelines because, if families do not understand the diagnosis, it is likely that their child will have late stimulation.¹¹

It is necessary to evaluate the results to clearly observe the understanding of the family members. For this reason, inquiries must be made in an attempt to expose what has been learned by the parents and what has not been clarified, so that health professionals will have confirmation of the family's understanding and they will know their work was successful.

So the sooner parents hear and understand the diagnosis, the faster they will understand their responsibilities and the more effectively they will seek early stimulation, orientation and development of their child.¹⁶ This understanding is decisive, since children with cerebral palsy need activities that provide them with general stimuli for their development, aiming at mitigating and compensating their limitations, considering that children stimulated by external factors create more independence despite of their conditions.¹⁷

Lack of communication between health professionals and families is also evident in the testimonies. This lack of commu-

nication causes the family to not understand the potential sequelae of cerebral palsy, and results in their own discovery of the process of growth and development of the child:

They did not tell me anything, but I was slowly learning about cerebral palsy (M3).

No, I did not know about the sequelae, they did not tell me much (M9).

Lack of communication between professionals and families can make it difficult for the family members to confront and adapt to the special needs of the child. In the results from other studies it was also found that the child is often discharged from hospital without their parents being aware of the diagnosis or being referred to follow up the child's development process in a tertiary referral hospital.^{11,14}

Over time, it is expected that coexistence with the child leads to a better comprehension of cerebral palsy different from the beginning. All participants reported having a better understanding of the child's condition, being aware of the limitations.¹⁸

As cerebral palsy is a condition with brain injuries, which parents find it hard to distinguish, health professionals should be clear when talking about the diagnosis since, in this way, it will be possible to raise awareness of care without any conflict of this understanding, as can be seen in the testimony of Mother 6:

Until nine months she seemed normal, because there is nothing in her body that shows it [...] later I noticed some things, she was already three years old when they gave the diagnosis, from there began the rush (M6).

The number of health professionals who have seen this child up to the age of three should be enough for her to be referred to a specialist center. After the evaluation, these professionals would observe the changes in her development. Even if there is no clear diagnosis, when a newborn goes to the Intensive Care Unit (ICU), parents expect clarification of the reason for the hospitalization. However, when professionals only provide daily news and then the child is discharged, the family believes the child is healthy and does not get treatment and rehabilitation to stimulate the central nervous system.¹⁴ Therefore, communication is essential for the early and appropriate treatment of cerebral palsy.

Some families realized for themselves changes in their child's growth and development. It is noted in the reports that discovery was late, causing parents to experience a moment of disappointment and incomprehension about what happened, because they had not understood and did not expect a child with a chronic condition.

We looked for more, because with two years he was floppy [...] I looked for resources, it was all I could do (M2).

With one year and 11 months I saw that she did not move her arm much, so I searched for explanations (M4).

She did not do the normal things children do [...] when she was two and a half years old I discovered that (M8).

In their speeches, participants show that they did not imagine, at any time, that they would be parents of a child with special needs. In addition, because cerebral palsy does not have traits or malformations, as it is a brain injury, symptoms are only noticed by parents over the years.

At first, it is difficult for parents to see differences between a child with cerebral palsy and other children without special needs, often due to the lack of experience or knowledge of each phase of the child's development, reason why they take some time to realize it. In cases of families that already have other children, comparisons begin earlier, so that, at some point, they realize there is some evidence that the child is different, and they soon start searching for answers.¹⁹

The need to exchange information between professionals and family members is one of the most beneficial aspects of care, since family support is indispensable for comprehensive care. Considering the undoubted importance of the family, specially when the patient is a child, health professionals should be attentive to the ways of communicating with family members and should respect them, since their participation in care causes the child to develop and have a healthy life.²⁰

Once the neurological damage is verified, the next step is brain stimulation, since there is no chance of cure, and there is a need for stimuli to promote the child's development and quality of life.²¹ It is therefore essential that the family is informed and that they understand their child's cerebral palsy diagnosis.²⁰

The limitations resulting from cerebral palsy require the follow-up of children in long-term motor, social, psychological and psycho-pedagogical rehabilitation programs. It is expected that the sooner the intervention begins, the better the results will be. A study emphasizing the importance of early access to physiotherapeutic treatment shows that children who start physiotherapeutic treatment until the eighth month of life have a better prognosis of motor development compared to those who started treatment late.²²

Therefore, it is possible to observe the importance of the communication between health professionals and the families of children with cerebral palsy, since the child needs a series of special care actions, including early stimulation. For this, families need to understand the diagnosis, which will only be possible with an effective communication between them.

By giving the participants the opportunity to report the experience of hearing the diagnosis of cerebral palsy of their child and understanding the child's possible special needs, it was possible to note that there was an initial shock with the new reality, mixed with fear of the new and the different, as it was something they had never imagined in their lives.

We were shocked at first, it was very hard (P1).

At first I was very concerned [...] in the beginning it was much worse, it was a shock (M3).

At first it was a huge surprise to everyone [...] I was frightened [...] at first I struggled (M4).

In the testimonies, it is possible to note the moment of confusion and distress in which these parents were when they heard the diagnosis of cerebral palsy and had to understand the child's condition. It is important to emphasize that everyone shows that the beginning was very disturbing. A similar result can be found in Pereira *et al.*²³ research, which states that the shock of the diagnosis has implications for the family, as family members see their life changing dramatically, even breaking with their own social roles.²³

After understanding the diagnosis, parents face an impactful moment as the child's condition differs from what they had imagined and expected. This understanding causes them to go through an initial moment of shock, resulting in an adaptation process that takes place in several stages, with different intensities.¹⁶

Despite dealing with the diagnosis, the family continues to go through troubles and difficulties, since life experiences are not a simple or inert process, but full of changes over time.²⁴ Therefore, even with the statements of the participants in this research about the desire for pregnancy, other feelings were revealed when they realized their child's condition, since at no time did they expect a child with special needs. Thus, some of them were in denial and other participants created other defense mechanisms that could give meaning to that event, as shown in their testimonies:

I was the one who did not want to accept that there was something wrong with her, when she could not sit down I would give an excuse (M7).

It is possible to note that parents' denial is a defense mechanism in order to "escape" from the situation they are experiencing. Negative emotions bring great frustration in the lives of these families, and denial makes it difficult to assimilate information that is passed on to parents, and it often undermines parent-child relationships, creating barriers to bonding.

Parents may deny their child's condition and set high expectations but, consequently, they get frustrated and struggle with the adaptations in their new routine.¹⁶ This denial may cause a delay in the treatment of the child with cerebral palsy, as parents deny the existence of the child's condition. However, this process of adaptation to the child with special needs is part of dealing with the situation experienced by the parents.^{5,25,26}

THE FAMILY'S PROCESS OF ADAPTING TO THE SPECIAL NEEDS OF CEREBRAL PALSY

Among the mechanisms families use to adapt to the situation, parents live the anguish of this immutable fact, as can be noted in some participants, and cling to the idea that the child being born different from the imagined was a designation of a higher power:

I thought it was going to be the end, but as I have a lot of faith I clung to it (P1).

He was meant to be like this and that is how he was born, I just thank God for him (M2).

If God gave me her like this, it was meant to be (M7).

She is the daughter that God gave me [...] God chose me (M8).

Testimonies refer to faith in God as a way of adapting and overcoming this care with the special child. Sandor *et al.*²⁷ acknowledge that, regardless of their religion, families believe in the presence of a God who has given them this child, relying on Him. This possibility of having spiritual support provides comfort for the parents of a child with cerebral palsy.

Some parents interpret, through their spirituality, that God granted them a child with special needs because they are extremely competent to take this responsibility.²⁸ This can be observed in the following reports:

I was the one chosen to take care of her and I will do that as much as I can (M6).

Because if God decides it, it's because you can handle it (M5).

In this case, faith in God is essential so that participants can have the strength to take care of the child, overcome the obstacles in the way, and accept that child. This spirituality motivates the family so that they can accept cerebral palsy, because there is still a sense of hope; therefore, it is easily justifiable.

Hope is present in the participants' daily lives, as the diagnosis brings many uncertainties along. This fact makes the family seek spiritual support grounded on faith and hope.²⁸ In addition, people often question the responsibility and tries to assign the blame on someone to get over the obstacles, as shown in the testimonies:

Her mother is diabetic and passed it on to her (P1).

First came the feet, then the head [...] then there was a lack of oxygen to the brain, so it was their fault (M8).

There was medical malpractice [...] a child like that, it was obvious that it was meningitis (M5).

Testimonies show that participants continuously searched for answers. As a result, parents try to find someone to blame for their children's special need, so that they can make some peace with it. Family members usually feel responsible for their child's disability, take the blame, and carry that feeling throughout their lives. When there is no one to blame, there is a search to find culprits, because at least there will be an explanation.²⁹

So, finding a motive for experiencing that situation may be part of the necessary process of adaptation for the normal development of the family's life.²⁹ For this painful situation to be faced and endured, family members search for culprits as a way to protect themselves so that the questions "why me?" "Why with me?" can be answered. Guilt is a way of understanding what happened to them, and they often blame themselves for past and present situations, understanding disability as a form of punishment. In some cases, guilt is transferred to other people (health professionals, relatives, the spouse, etc.), simplifying their responsibility in the scenario. Therefore, they try to find reasons that satisfy them, which is part of the process of acceptance and reestablishment of the family.¹³

Another variation of this guilt is when parents blame themselves for believing that they were not able to conceive a child without disability. This behavior leads them to misunderstand the causes of cerebral palsy, but helps them to accept the child, because once there is a reason, there is a sense of relief and this contributes to strengthening the bond.⁵

When they notice that there is something wrong with their child, parents seek a diagnosis and are faced with lack of information. The only way out is to turn to sites, books, among others, on their own to find explanations. Searching for knowledge is the first step towards accepting the child's chronic condition, in addition to meeting the family's need for information to investigate the cause, diagnosis, and prognosis, and to know the right way to care for this child.²⁰

Then, after this difficult process, they are able to understand and comprehend the diagnosis and, even if they did not

understand what it was during the medical appointments, several mothers search information about cerebral palsy by themselves wherever they can.

I understood that I was going to have difficulties at the beginning, not for my entire life. [...] I began to investigate and to learn, I searched the Internet (M4).

I did not understand much, but I was referred to a lot of places. Luckily one of them was the APAE [...] there I understood (M7).

I searched for myself, because no one explained to me. I do my searches until today (M6).

These reports highlight the importance of the individual search for information, since the attempt to learn the best way to act with the child demonstrates the level of commitment and care provided by these families. For a comprehensive care and stimulation of this child to occur, it is often necessary search of information, because if these families have specific knowledge, they will better adapt and dedicate to the child.

When parents are faced with their child's condition, they consciously or unconsciously seek and need to understand what happened and what will happen from that moment on.^{4,15} Thus, a journey begins between doctors and examinations, until they find someone or something that provides an explanation.¹⁹

This process to understand the chronic condition is often slow, but at the moment of acknowledgment, there are several changes in the parents' lives, who search for information to benefit the child in need of special care.²⁵ Thus, it is necessary to understand that cerebral palsy is a complex condition, which is difficult to understand in a simple way for lay people, so there is concern about these searches without the assistance of a health professional capable of helping in the understanding. However, helplessness and, often, lack of commitment on the part of health professionals with the situation instigate the family to search for answers about the child's condition.^{24,30}

Thus, health professionals can help with interventions capable of enhancing the communication and development of strategies that offer support, attention and listening to the family. However, the information obtained by the family often comes from Internet searches and/or from the interaction with other people who experience a similar situation, which is a communication that addresses the complications of caring for a child with cerebral palsy and the methods of overcoming and adapting. Therefore, the ideal situation would be that health professionals could be attentive to this communication, in addition to being prepared to solve doubts and help so that care to this child with cerebral palsy is comprehensive.

FINAL CONSIDERATIONS

In seeking to know the family's reactions to the diagnosis of the child's cerebral palsy, it was possible to understand the processes this family goes through during the moment they hear the diagnosis. It was concluded that the way health professionals express themselves during the diagnosis process was inefficient, as shown in the participants' testimonies. In view of this, the parents of these children remained with doubts, generating a delay in the process of adaptation to the child with special needs.

In view of the above, it was possible to note that most of the interviewees were outraged at the health professionals, who did not establish a relationship with the family members. Therefore, the study highlights the importance of bonding and establishing good communication between health professionals and the family members of a child with cerebral palsy. It should be noted that this relationship contributes to the way diagnosis is given and understood, up to acceptance and care of this child. In addition, it helps to create support networks for care of the child and the family members.

In view of this, this study is expected to enable health professionals to reflect, in order to rethink the assistance provided to the families of children with cerebral palsy, as well as their commitment as members of a health care institution for the population. In this sense, the actions implemented should help in the process of developing conducts, in which health professionals can keep a dialogue accessible to family members. In addition, they should provide comprehensive care so that parents understand the whole process of caring for a child with cerebral palsy and can be referred to a network of specialized services, thus providing a more humane care to the child and the family.

It is also recommended, due to the lack of studies addressing the topic, that more studies are carried out by the area of nursing, whether of teaching, research or continuing education, to contribute to the improvement of the quality of life of these children with cerebral palsy and their family.

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