Original Article

Telling the mother that her newborn has a disability*

Comunicando à mãe o nascimento do filho com deficiência

Comunicando a la madre el nacimiento de un hijo con discapacidad

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ABSTRACT

Objective: To know how health care team members inform mothers that their newborns have disabilities. **Methods:** Qualitative descriptive study. By conducting semi-structured interviews, data were collected from seven mothers whose children have disabilities and are provided care at Associação Pestalozzi in Campo Grande, MS, Brazil. The reports of the mothers were organized into theme units and categorized according to Bardin. **Results:** Health professionals fail to inform mothers of the disabilities of their children in a clear manner; their professional approach is closed to dialogue and the information on the child's prospects is limiting and pessimistic. **Final considerations:** Health professionals must be prepared to disclose information to mothers, showing them the available possibilities of development for their children and providing the necessary attention to the feelings experienced by the parents, promoting their trust and confidence, and helping them to deal with their difficulties.

Keywords: Disabled children; Maternal behavior; Mothers; Patient care team

RESUMO

Objetivo: Conhecer como a equipe de saúde comunicou à mãe o nascimento do filho com deficiência. **Métodos:** Estudo descritivo de abordagem qualitativa. Com entrevistas semi-estruturadas, coletaram-se dados de sete mães cujos filhos têm deficiência e são atendidos na Associação Pestalozzi de Campo Grande, MS. As falas das mães foram organizadas em unidades temáticas e categorizadas segundo Bardin. **Resultados:** Os profissionais de saúde não informam o diagnóstico de deficiência do filho à mãe de maneira clara; a abordagem profissional é fechada ao diálogo e as informações sobre o filho são pessimistas e limitantes. **Considerações finais:** Os profissionais de saúde precisam estar preparados para fornecer informações à mãe e mostrar as possibilidades de desenvolvimento do filho, além de proporcionar a atenção necessária quanto aos sentimentos vivenciados pelos pais, a fim de garantir confiança e segurança para o cuidado do filho, ajudando-os a superar as dificuldades.

Descritores: Crianças portadoras de deficiência; Comportamento materno; Mães; Equipe de assistência ao paciente

RESUMEN

Objetivo: Conocer cómo el equipo de salud comunicó a la madre el nacimiento de un hijo con deficiencia. **Métodos:** Estudo descriptivo con abordaje cualitativo. A través de entrevistas semi-estructuradas, se recolectaron datos de siete madres cuyos hijos tenían deficiencia, atendidos en la Asociación Pestalozzi de Campo Grande, MS. Los discursos de las madres fueron organizados en unidades temáticas y categorizados según Bardin. **Resultados:** Los profesionales de salud no informan a la madre el diagnóstico de deficiencia del hijo de manera clara; el abordaje profesional es cerrado al diálogo y las informaciones sobre el hijo son pesimistas y limitantes. **Consideraciones finales:** Los profesionales de salud precisan estar preparados para dar informaciones a la madre y mostrar las posibilidades de desarrollo del hijo, además de proporcionar la atención necesaria en cuanto a los sentimientos vivenciados por los padres, a fin de garantizar confianza y seguridad en el cuidado del hijo, ayudándolos a superar las dificultades.

Descriptores: niños portadores de deficiencia; Comportamiento materno; Madres; Equipo de asistencia al paciente

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INTRODUCTION

When a child is born, there are usually many expectations and celebrations, doubts and apprehension in relation to the baby's health, life and future. Such feelings get stronger when parents are told that they had a disabled child. In this situation, parents often face hard times because of emotional factors and intense frustration(1-2).

Hardship, pain, embarrassment, tears, and confusion are often consequences of the disability for all family members, besides the huge amount of time and resources needed to care for the child(3).

The way parents receive the news about their child's disability can influence the parents' reactions decisively(4) , because the diagnosis of disability seems to create a critical impact situation, characterized by feelings such as pain, distress, fear, guilt and shame(5) .

Health professionals often forget that the birth of a child who has special needs does not change the reality that parents are only human beings, have feelings, and experience fears and doubts(3, 6).

The lack of preparation by health professionals working with the family does not promote their commitment to their activities, and parents are not satisfied with the way they are treated(7).

That situation gets more serious when health professionals emphasize the limiting aspects of the disability, instead of showing the possibilities of development, available ways to overcome difficulties, guidance centers for the family, early stimulation resources, and reference centers to assist children with special needs(8).

The message that the nurse and other members of the healthcare team can give to parents at the moment of the diagnosis is that they are there for them and, little by little, they can help the family to visualize the future potential of their child. It is necessary to give the family the message that a new challenge has just started and it is time to share feelings and emotions(9).

A special child in the family makes all members experience shock and fear in relation to the situation, as well as pain and anxiety when imagining what future consequences will ensue(10).

Being parents of a child with special needs is a new and complex role, so an understandable medical diagnosis is fundamental; consolation for guilt, fear, doubt and some ideas about the future, both for parents and child; a lot of hope and encouragement(3) are interventions that can help them accept the challenge that they must face.

However, many times parents get confused at the moment of the diagnosis and receive no proper guidance, which can interfere with their relationship with the baby. They may also harbor false expectations, and that will influence accepting their real child or not(11). Thus, the strategy that most families use to face the special needs of their child is to search for information about the disability and what the child's development process will be like(12).

The family is very important in that situation because the disabled child feels safe to learn and grow in order to overcome the restrictions and do different tasks in the family. The family has a special role in the routine of a disabled child(13).

Therefore, the health team must be sympathetic in order to help parents raise a disabled child. They must be comforted about feelings like guilt, doubt and fear, have some idea about the future of the parents and the child and, mainly, have hope and encouragement to accept the challenge that they will have to face(10).

The way in which the health team informed the mother that her newborn had a disability was studied.

METHODS

This is a qualitative descriptive study. Bardin's (14) method and category analysis were used. The data were collected using semi-structured interviews based on two guiding questions: "How did you know about the disability diagnosis?" and "What did they tell you?"

There are fifteen mothers with disabled children who receive care at the Associação Pestalozzi Health Unit in Campo Grande, MS, but only seven agreed to participate in the study. Mothers were the only ones included because, most times, they are the ones who take the child to the health unit.

The mothers interviewed were between 24 to 46 years old. Their children were between 4 and 6 years old and their mental disabilities involved genetic and congenital malformation.

The term "special needs" is used at the institution because it is an anthropological and educational concept, and it was used during the study too; however, in literature, quotations of the term "disability" are also used.

A disability is each and every need resulting from a certain life scenario, specially from characteristics of the incapacity that affects the person who is disabled. They must be considered so that that person can enjoy all social activities, rights and duties. The Brazilian legislation highlights the need of assuring specific conditions to provide disabled people with equal opportunities(15).

The interviews took place at Associação Pestalozzi, in Campo Grande, MS, in May, 2006 and they were recorded with the mothers' permission.

The talks were totally transcribed and were read in detail, in order to codify them, that is, identifying an excerpt to choose the theme units and then classify them in two categories: "Being told about the child's disability diagnosis" and "Mothers receiving information". In the transcripts, the participants were identified by mineral names – Amethyst, Topaz, Sapphire, Ruby, Jade, Emerald and Tourmaline – to remain anonymous.

Associação Pestalozzi in Campo Grande was previously questioned about the study and formally agreed to it. The University for the State and Pantanal Region Development Ethics in Research Committee also approved the research involving Human Beings at the and, in compliance with Resolution n.º 196/96, mothers who participated in the study signed a Free and Informed Consent Form.

RESULTS

Being told about the child's disability diagnosis

Those mothers responded to their child's disability diagnosis in several different ways, characterizing the following theme units: "Looking for medical help", "Professionals do not give any information during the visits", "Professionals give technical information", "Receiving clear information in a reserved place", "Receiving information with no possibilities of dialogue and in an inappropriate place" and "Receiving a written report".

Being clearly informed about the diagnosis and the necessary measures for the child's treatment is essential to the mothers. Thus, the kind of approach used and emotional atmosphere at that moment are very important (9). If the mother does not receive the necessary information about her child's disability, she looks for help in order to have her doubts clarified.

"I noticed at the moment she was born. But we notice and we do not ask because we do not want to hear the answer. It is fear, you know? (Amethyst)

Mothers report how the professionals told them about the diagnosis of their child's possible disability.

"So, at the moment he was born, in the surgery room, the doctor only said that he had a congenital malformation. He did not say exactly what the problem was" (Ruby).

If the diagnosis is not well understood, it is possible to imagine or fantasize situations about the child's disability.

"As I had not seen the child, he said: "Your son has a congenital malformation". I imagined a totally crooked, disabled child ..." (Ruby).

It is very important to give clear information, in an open atmosphere and in a private environment so that parents can feel comfortable to ask questions and decrease their anxiety(3, 17) :

"Then she took me to a small room and told me... She said: 'Have you noticed something different with your baby?' ... And she started to explain it" (Topaz)

"I still had the caesarean stitches, seven days after I had the baby she told me in the corridor..." (Diamond)

"Then he explained, but he is very rude, he did not want to talk a lot.." (Emerald)

Some mothers say that they have all the information written on a paper:

"The first doctor wrote on a paper, so I have a paper with everything written at home" (Emerald)

Therefore, the way mothers responds to the diagnosis and the attitude of the person who gives the information may convey a sense of trust and help the mother to understand better the situation she has been experiencing, or not.

Mothers receiving information

Mothers' report about what kind of information they received at the moment of the diagnosis of their child disability could be grouped into the following theme units: 'Getting hope for the future', 'Looking for other professionals' help', 'Looking for information about the pathology', 'Receiving the diagnosis according to the needs for that moment', 'Receiving pessimistic information' and 'Receiving guidelines about the visits and care provided by the multi-professional group'.

Many professionals can give real and simple information and at the same time, give parents some support and hope about the future(18).

"First she told me that, because it is a degenerative disease, there is no cure... But her clinical conditions are stable, the damages that were supposed to happen have already happened, now we've got to live with it ..." (Jade)

Some mothers received guidelines from other professionals during the following visits and, because they wanted to know what their child's problem was, they needed to have to the same information from different professionals until they could accept the diagnosis(17).

"Then, that other doctor showed me a picture, so that I could see how it was, to explain to me because I had never heard about that..." (Tourmaline)

"Then he examined the heart...when he did that, he said: 'No, your daughter has systolic murmur". Then everything got calmer and calmer..." (Diamond)

Some mothers did not know about the pathology and/or disability, but they started searching for information and learning through other sources, like books and magazines, because they needed to live together with the child(6, 19).

"…everyday you find out about something new, right? People talk to each other, you research …look for something in the Internet" (Ruby)

The health professional should be able to effectively become closer and closer to the family in order to know their realities and needs, so as to promote a better adjustment of the care to be provided. However, there are professionals who believe that they know the child and that they have the power to decide on which methods to use, and they treat parents as though they were unable to take care of their own child. Many times, they do not give any hope about the future to the family(7).

*"The doctor said… that the child's brain was not good, the heart was not good, the kidney was not good, that she was blind, deaf, dumb, everything that you can imagine about a child …then I only asked her if she (the baby) was at risk and she said: "Look mother, put it in your mind that she is a child of God; she is a child that should have never been born"… (*Diamond)

The same mother suggests a way to talk about the diagnosis:

"Depending on the way you say things they get so much better, right? She could have sat there and said: 'Look, mother, I suspect that'. But no... Talking the way she did… you think… It's over'" (Diamond)

When informing the diagnosis, the health professional can be an advisor, giving information about multi-disciplinary group services in order to decrease the time between the diagnosis and the beginning of specialized treatment(3).

"I am going to send her to school". Then she started to have physical therapy and everything else that had to be done .As soon as he (the doctor) requested the exam, he already started working with her" (Amethyst)

"The mothers interviewed did not understand the information about the diagnosis that the health professional gave – an important situation, because, if they do not understand that, they can not guide their actions. In the professional's attitude, the mother notices a lack of involvement and support to adapting to the situation she is experiencing(10).

In a study about the mothers' most common complaints about the diagnosis, most of them stated that the professional often did not tell them what was really happening, although it was obvious that something was wrong(3).

There are some cases that the health professional can omit some important information because he/she is afraid of making the parents vulnerable, or even using an extremely technical language that could make it difficult for parents to participate in the conversation(16).

The studies show that most professionals are not prepared to give the news, and as such they make that moment a destructive and traumatizing event for the parents(11).

In face of that, better ways to inform parents of a disability will minimize the hopelessness experienced by them. On the other hand, if these conditions are not met, it will be hard for parents to cope with and adapt to a lifelong situation. Thus, the way in which parents are informed of such a diagnosis is relevant, because it will affect the beginning of a long process of adjustment (1, 19).

Sometimes, written reports about the kind of disability and treatment plans are viable ways to inform and facilitate parents' understanding of the reality(3).

The nurse must be present when the diagnosis is confirmed in order to assist the mother in a human way. The complexity and the impact of the diagnosis on the family and the need for assistance to all those who will live with the child by skilled professionals that can be trusted must be taken into account(13).

Health professionals must talk clearly, slowly, honestly, and responsibly to parents about the diagnosis, and offer to talk to the family at the moment of the diagnosis and whenever they find it necessary. They must comfort the mothers, telling them what their child's problem is and what it means, giving them hope about the future and avoiding false information or no information at all(4, 20 – 21).

All those aspects show how important health professionals are in this process, not only because they are the first ones to be in contact with the parents before, during, and after the news, but also because parents rely on them.

FINAL CONSIDERATIONS

This study described the way health professionals told some mothers about their child's disability and revealed that many of them are not prepared to inform parents of the diagnosis in a clear and proper way. That situation allows mothers to imagine and fantasize things, increasing impact of the problem on them. That may be happening because those professionals do not have the academic background for that moment and there are no organized services available to help those families once such a diagnosis is done.

So, some mothers reported that some professionals do not disclose the information during the visits or that they received technical information in a setting where a dialogue was not possible, which forced them to look for other professionals to help them with their doubts and decrease their distress and anxiety.

Health professionals, especially the nurses, can show the possibilities for those children's development and give the necessary attention to the parents' feelings in order to provide them with trust and confidence to take care of their child, helping them in overcoming difficulties.

The nurse and other health professionals need to be prepared, supporting and following the parents up, helping them raise their disabled child in a healthy way and promote the potential abilities of the child by providing human, welcoming, and individualized assistance.

REFERÊNCES

1. Brito AMW, Dessen MA. Crianças surdas e suas famílias: um panorama geral. Psicol Reflex Crit. 1999; 12(2):429-45.
2. Souza LGA. Cuidando do filho com deficiência mental: desvelamentos de vivências de pais no seu ser-com-o-filho [tese]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2003.
3. Buscaglia L. Os deficientes e seus pais: Um desafio ao aconselhamento. 4a ed. Rio de Janeiro: Record; 2002.
4. Sinason V. Compreendendo seu filho deficiente. Rio de Janeiro: Imago; 1993.
5. Canho PGM, Neme CMB, Yamada MO. A vivência do pai no processo de reabilitação da criança com deficiência auditiva. Estud Psicol (Campinas). 2006; 23(3):261-9.
6. Silva NLP, Dessen MA. Crianças com síndrome de Down e suas interações familiares. Psicol Reflex Crit. 2003; 16(3): 503-14.
7. Paniagua G. As Famílias de crianças com necessidades educativas especiais. In: Coll C, Marchesi A, Palacios J, organizadores. Desenvolvimento psicológico e educação: Transtornos de desenvolvimento e necessidades educativas especiais. 2a ed. Porto Alegre: Artmed; 2004. v. 3. p. 330-46.
8. Maciel MRC. Portadores de deficiência: a questão da inclusão social. São Paulo Perspect. 2000; 14(2): 51-6.
9. Barbosa MAM, et al. A vivência da mãe com um filho deficiente na perspectiva fenomenológica. In: Ivo ML, Nunes CB, Zaleski EGF, Barbosa MAM, Pádua AR, organizadores. Dimensões do processo de cuidar em enfermagem. Campo Grande: UFMS; 2004. p. 161-81.
10. Barbosa MAM. Compreendendo o mundo-vida da mãe com um filho deficiente [tese]. São Paulo: Universidade Federal de São Paulo.Departamento de Enfermagem; 2000.
11. Höher SP, Wagner ADL. A transmissão do diagnóstico e de orientações a pais de crianças com necessidades especiais: a questão da formação profissional. Estud Psicol (Campinas). 2006; 23(2):113-25.
12. Silva NLP, Dessen MA. Deficiência mental e família: Implicações para o desenvolvimento da criança. Psicol Teor Pesqui. 2001; 17(2): 133-41.
13. Oliveira RG, Simionato MAW, Negrelli ME, Marcon SS. A experiência de famílias no convívio com a criança surda. Acta Sci, Health Sci. 2004; 26(1):183-91.
14. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 1979.
15. Brasil. Ministério da Saúde. Secretaria de Assistência à Saúde. Manual de legislação em saúde da pessoa portadora de deficiência. Brasília: Ministério da Saúde; 2003.
16. Braga MR, Ávila LA. Detecção dos transtornos invasivos na criança: perspectivas das mães. Rev Latinoam Enferm. 2004; 12(6):884-9.
17. Klaus MH, Kennell JH. Pais / bebê: a formação do apego. Porto Alegre: Artes Médicas; 1993..
18. Guiller CA, Dupas G, Pettengill MAM. Criança com anomalia congênita: estudo bibliográfico de publicações na área de enfermagem pediátrica. Acta Paul Enferm. 2007; 20(1):18-23.
19. Bregantini EC. Deficiência. O respeito às diferenças. Ser Médico. 2002; 20:32-3.
20. Silva MC. Aprendendo a descobrir o mundo. Dourados (MS): Faculdade Teológica; 2003.
21. Oliveira NFS, Costa SFG, Nóbrega MML. Diálogo vivido entre enfermeira e mães de crianças com câncer. Rev Eletrônica Enferm [periódico na Internet]. 2006 [citado em 2007 Mar 2]; 8(1):[cerca de 14 p.]. Disponível em: http://www.fen.ufg.br/revista/revista8_1/original_13.htm