DOI: 10.4025/cienccuidsaude.v12i4.18826

FAMILY CHILD WITH SPECIAL NEEDS OF HEALTH: THE PROCESS OF COPING AND ADAPTATION[1]

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ABSTRACT
The study aimed to know how to get the process of coping and adaptation of the family in the care of the disabled child with special health care needs, in order to contribute the development of possible strategies to facilitate the process. Descriptive research of qualitative nature, held in Family Health Units from a city of Paraíba interior. The data were collected in the months of March and April 2012, through open interview with eight mothers of children aged 1 year and 11 months and 10 years of age with auditory disabilities and multiple special needs. For analysis followed the methodology of the Collective Subject Discourse. Mothers demonstrated a hard and lonely coping and adaptation to the reality of caring for a child with special health needs for lack of necessary support. Thus, it is essential to the existence of support networks for the binomial-child family as coping allowance.

Keywords: Child. Child Care. Family. Pediatric Nursing.

INTRODUCTION

Children with Special Health Needs are an emerging children's group, that has continuous care demands, temporary or permanent, and depends on a multitude of special services, such as health and social, beyond required services by children generally. This profile includes children who exhibit motor conditions, functional, behavioral, and emotional or developmental constraints or incapacitating, those with disabilities or chronic disorders and also those which have the greatest potential risk to present them(1).

In this sense, whereas the first space of socialization of a person, with a handicapped child birth, is the family atmosphere, which undergoes changes, not only in terms of reactions and feelings of its members, as well as their structure and functioning. In this process, the family often needs to rethink its organizational shape structure as a group, because the care for the child with disabilities and special health needs requires constant presence of a caregiver(2).

The deficiency will always have individual significance and consequently different repercussions in every member of the family. By understanding that she will have limitations for the whole life, this will require that they adapt to the new reality. Thus, the way each person fit, to deal with disability news, is individual and will influence on family dynamics and on their interaction with the child(3-4).

Since the family is made up of elements that contextualize the community and society, establishes links with the outside world, it is an open system, which, at the same time in which influences, is also influenced, contributing to the development and security of its elements in various ways: by satisfying their most elementary needs; facilitating a coherent and stable development; fostering a belonging climate, very dependent on how it is accepted in the family(3).

In this way, it will be with family members that the handicapped child with special needs

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will sustain personal relationships closer and important, in many cases, the only(5).

Among the members of the family, the mother is the main agent of caring for a child with special needs, since this requires, in some cases, highly supervised attention. In this sense, the mother becomes the most required and the most involves the role of caregiver, not being rare sometimes on who takes on the full responsibility of watching emotional, physical and financial(6-7).

Generally, the families who care for children with special need they feel overburdened by excess of responsibilities, either time devoted, lack of support and social support . The main difficulties are the social, physical and emotional overburden, and the complications that result in permanent monitoring need by ambulatory health care services and rehabilitation(8-9).

Still, the family just looking for ways to adapt to the new reality, reacts by expressing emotions, which range from confusion until the fear of incompetence and develops ways to deal with the situation, facing, i.e. doing what it is necessary, dealing with the problems and advancing(8-9).

In this sense, it is justified that this study, such as allowance for inclusion of assistance to families of children with special health needs, is essential for a humanized attendance, effective and integral. Such assistance should include psychological and social support actions, guidelines for carrying out the activities of daily living, rehabilitation basic actions and the provision of specialized support in case of hospitalization or domiciliary interment (8-9).

In the face of this reality, this study aimed to see how the process of coping and adaptation of the family in caring for a child with special health needs, in order to contribute to the elaboration of possible strategies to facilitate the process and widen the support network.

METHODOLOGY

This is a descriptive exploratory qualitative study carried out in the period from March to April 2012, in Family Health Units in the urban area of Paraíba municipality. The study population was composed of eight mothers of disabled children with special health needs. The selection of these made by prior consultation to the medical records of families registered in these units seeking to identify children with any disability. From this information, previous contact with the family, checking the existence or not of special health needs, such as demands of technological development, medicated, usual and mixed.

It was used as inclusion criteria: mothers of handicapped children with any special health need; be registered in one of the Family Health Units of the urban area of the municipality under study. As a criterion of exclusion: mothers who present some difficulty of communication. The project was submitted to the Committee of Ethics Research under protocol number: 20111612-070 as advocating Resolution 196/96 of the National Health Council, having received a favorable opinion. Participants signed a Free and Informed Consent.

The data were collected in the months of March and April 2012, by interview technique, guided by a semi-structured script, with the following main issues: 1) How was for you to face the needs of your child care demand and adapt to them? 2) How did you/can perform the adjustments in your life to take care of your child?; 3) Did/Do you need to use social support networks to take care of your child? As hospital care, primary care services and family or neighbors support?

All the interviews had an average duration of 40 minutes and were carried out within the framework of the participant domicile, after prior scheduling according to the availability and upon signature of Free and Informed Consent (TCLE).

For data analysis, it was used the Collective Subject Discourse technique (DSC). As understood by their authors, it consists of a discourse analysis mode obtained in verbal statements or in any discursive manifestation, that can be finding in texts and written documents. Structurally, it was organized from the use of methodological figures designated as: Anchor (A); Central Idea (IC); Key Expressions (EC) and the Collective Subject Discourse (DSC). The meanings of these figures or steps of a procedure test give the notion of seizure process of meanings, that arise in all the lines, which display a collective thought or the representation of the group on given theme or issue(10).

In the testimonies interpretation, were established Anchors (A), which resulted in a categorical set of three Central Ideas (IC), in which stood out the process of coping and adaptation in caring for disabled children with special health needs for the family, namely: 1) Lonely coping of adaptation process for the child with special needs care; 2) Life experience and the contribution to the confrontation issues involving the child care with special needs and 3) The need of social support networks of children care with special needs. From the Central Ideas the synthesis-speeches were built, bringing together all elements of various testimonies, organized according to the answers given to the questions of the interview script.

RESULTS AND DISCUSSION

This is a descriptive exploratory qualitative study carried out in the period from March to April 2012, in Family Health Units in the urban area of Paraíba municipality. The study population was composed of eight mothers of disabled children with special health needs. The selection of these made by prior consultation to the medical records of families registered in these units seeking to identify children with any disability. From this information, previous contact with the family, checking the existence or not of special health needs, such as demands of technological development, medicated, usual and mixed.

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The speech demonstrates how difficult and lonely is for mothers the process of confronting the reality of caring for a child with special needs and adapting to it. In the experience of both the initial phase, with the discovery of the diagnosis, as following the procedure, mothers refer to not have received necessary support, either by health professionals, the family, or even the interpersonal links expanded, as friends, colleagues and the relations established in the community.

1 Central Ideia **-** Lonely coping of adaption process for the child with special needs care.
DSC: I suffered a lot for my son's life, because everything I was doing to take care of my son [...] I'm adapting slowly [...]He relies heavily on me, he is very different from other children his age. I'm still adjusting to the life of my son.[...] Because have that difficulty, people look him differently, teaching him to get used to it, watch him closely, especially the other children who are treating him badly, by surname, and saying things to him. [...] It is being still of great difficulty. Some things he speaks, we understood, then I confirm one thing and when I see he is doing something else wrong.[...] It was hard, I still didn't fit in, I'm adapting slowly because to me is being very difficult, both for me and for him, both of us feel very prejudice [...].Oh, I always ask help to Jesus, because only he who has to give, he is the great power of the life of the people.

It is known that the adaptation of the disabled child with the family after the communication of the diagnosis of disability is closely related to the support, confidence and real clarifications in first words about what happened(4). In this moment, the families need support and reception, receive clear guidance on disability, including the different alternatives and possibilities for help. In this way, the support and the mediation of professionals can minimize the impact, showing the positive possibilities, setting up in important role with these families(7).

In this perspective, the family of the disabled child needs access to the sources of social support, which transcend the professional and family relations. The community and partnerships of various social segments can be configured in support to the families of these children. This support can be a useful information, someone to listen, an encouragement, money, equipment and contribution(7,11). In this context, social networks are very important because they influence in the formation of the individual identify, reflecting on how to face and adapts in crisis situations(11).

As regards of coping issue, the mothers reported their religion as a searching for help and personal empowerment, to follow through the caring for the child process. Believing in something bigger and more powerful is important, it helps individuals to face the adversity and overcome the negative feelings, sometimes generated in the course for the child care process.

The mechanisms by which faith and belief act for improvement of the general condition of people are still unknown. However studies have shown that families, followers of religious beliefs, attach to the faith a significance to the confrontation of the chronic condition of the son(12).

The spirituality action transmits safety, serenity to the family and control of stressful situations through which they pass. They are coping mechanisms found to avoid a more intense physical and mental imbalance(9). Thereby, spirituality has contributed to the improvement of the health status as also enhances the emotional state for bringing hope, forgiveness, altruism and love. In this sense, stress is reduced, allowing the choice of the best strategies to deal with the problems(12).

On most occasions, the care provided to a child with special needs fall on the figure of the woman, since she is assigned the role of housework, family relations and child-rearing. However the solitary experience of this stressful experience may lead them to isolation, affecting their interpersonal relationships, that the presence of a child, regardless of any factor, will modify the whole family dynamic(7).

The answer that the family will give this challenge will depend on the past experiences, the economic situation, as well as the ethnic background and family relations, among other influences, which will determine whether the challenge of creating, care for and educate your child will be faced(9).

The experiences, that mother spend with special needs children, are unprecedented situations, which become knowledge lived and that serves as a personal learning. Although, at the beginning, the majority refers to difficulties in the actions of care, they acknowledge that, in the experience of those cases, it is possible to acquire the competence to learn and also to perform tasks never performed before, demonstrating a positive stance in the confrontation.

2 Central Idea - The life experience and the contribution to the confrontation of issues involving the child with special needs care.
DSC: My life experience has helped me enough to tackle the problem of my son.[...] At the beginning it was difficult because I never took care of a disabled person, so for me it was very difficult, I saw on the outside and never thought this would happen to me. My life has changed a lot.[...] I learned and now I'm learning more every day and I am also trying to better myself to help him and the others, because we don't live only with our son.[...] I did everything I could, I went looking for strength in myself. I learned a lot with my son.

It's in the family atmosphere that the difficulties appears, defying his parents to fulfill the educator of children role, making them to participate actively in the current society, which emphasizes aspects such as efficiency and effectiveness(13).

Interpersonal relations between the family and the child with special needs are complex, if the perception of the illness in the family is negative, knowing that this is due to the fact of creation, of the past and philosophy of each of the members, will determine negatively the way of interpret the disability, as well as the coping capacity of care process for the child.

The experiences, learning and culture, in which families live together, are directly responsible for upsetting thoughts and concepts on disability, and that can be awakened within familiar by the impact of the birth of the child with special needs. However it is clear that parents, especially mothers, have not received the necessary support, to deal with a child with so many demands for care(14).

However, the family is the basis for the creation of this child, being the mother, the primary caregiver, which inevitably have to face the challenge of caring for, taking into account all their experience of life. The demands of care required by a child with special health needs are intense and constitute challenges to them.

By being an essentially feminine activity, the woman not only has the task of nursing, but also to learn to take care of. This implies the necessity of having access to information related to knowledge of the field of health. Caregiver mom needs a "time", which is not chronological, but yes, singular to each one of them, depending on its context, of his story life, the smaller or larger influence of sociocultural matrix, of care, to elaborate mechanisms to help in the confrontation(15).

Thus, the social support network to which it has access, the sharing of information, experiences and social interactions and experiences with healthcare professionals in a dialogical relationship, can contribute to the exchange and the sharing of experiences of care with the other members of their social support network.

3 Central Idea – The need for social support networks of children with special needs care.
DSC: In the beginning was very difficult, because it only had a small clinic to attend my daughter, then I got a better place and now she's distant.[...] In the beginning was very difficult because here (where he lives) had no specialized network and now we're going to Recife to do treatment on the AACD, he goes there to do some tests like tomography, resonance.[...] The only support network that I needed was the NASF to be attended by speech therapist. So it was from that point that they sent me searching for a doctor and take her. [...] I needed all the doctors trimmings, psychologists, speech therapist, and also needed to take him to the doctor in Natal.[...] And I always take her to make treatment with the therapist and speech therapist. I haven't tried other because I have to leave the town.

The quality life of the families of children with special needs are affected by socio-economic factors and, consequently, the absence of specialized centers for children treatment(8). Families seeks ambulatory health services, represented by the Family Health Units, to consolidate the domiciliary care, in more specialized care environments, seeking the implementation of the law, a reference system and against reference really resolutive(8).

In the process of child care with special need, the family goes through stressful and difficult moments, maybe alone were not able to overcome and be able to move on. Front support to these situations imposed by disabilities can be offered over the network and social support for families to have and use in different moments(12).

Social networking has fundamental relevance, since it is an essential resource to assist the family in different moments. Thus, health professionals must recognize its importance and work on it in order to strengthen the coping mechanisms and encourage adaptation.

The customer care demands presented by children with special health needs, implies the establishment of a social network formed by institutional participation, community and familiar, little explored in the studies developed with this children's group. Social networks are collective structures, able to make their subject, empowered, reflective and sympathetic in their actions and relationships, aware of their attitudes(15).

Networks can be understood as a system composed of several social objects, i.e. people, functions and situations that offer emotional and instrumental support to the person, in their different needs. The emotional support, refers to the affection, approval, sympathy and concern for the other, and also the actions that lead to a sense of belonging to a particular group(16).

Although the family is with open arms to receive such support, it is still insufficient, despite their importance in overcoming the obstacles imposed by disabilities, especially when there is a need for many care, that members-guzzling, especially mothers. Every time the family is supported, assisted, aided by people, which are available at certain times of life, is receiving necessary social support and essential to supply their needs(12,16).

The social support received and perceived by people are fundamental to the maintenance of mental health, for the confrontation of situations and also for the relief of physical and mental stress, and for the promotion of health and well-being(16). Thus, the nursing care by listening, dialogue and advice gained prominence as a family support for children with special health needs in the process of confronting the situation experienced and adaptation(17).

FINAL CONSIDERATIONS

This study points out that the main difficulties presented by the mothers of children with special health needs during the process of adaptation to the care of them, relate mainly to the lack of support from other family members, health services and society in general. The absence of a social network, which offers the means to deal with the reality of having a handicapped child with special needs, hinders the acceptance and the necessary confrontation of the family.

This support is attributed any activity, which makes it possible to share experiences with direct effect on the well-being of the child and the family, configured as emotional, material/instrumental and educational. It can be related to the emotional, esteem, affection, and approval actions, which lead to the feeling of belonging to the group; the material/instrumental, financial assistance, the division of responsibilities and some types of services that provide assistance in this regard; and the educational or informative, that in order to facilitate the exchange of information between people, to make them feel safer challenges.

A network of family support favors the formation of links and structuring of life of children with special health needs, expanding its possibilities from the self-esteem from the affectivity. This network cannot be ignored as regards the development and socialization of the child. Through the care relationships the family transmits values such as tolerance and respect for differences, cooperating for a proper development, especially when social services are inadequate and insufficient public policies.

It is important that the nurse and other health team members, within that perspective, having as objectives mediate difficulties that the familiars has in the process of monitoring and treatment of their children, including interpersonal relationships within and outside the family. For being a fundamental professional in the act of doing the best for everyday care of the individual, the Nurse is able to contribute to the restructuring of these familiar routine, promoting host and relevant guidelines to each case.

It is believed that, to take care of the family, the Nurse should evaluate the family in its structure, functioning and development. A key component is the evaluation of how the family relates to the community in which it operates, how to use the features and the way social support networks accesses. In this way, it is possible to identify which resources have been used and how you can help them to improve them.

It is necessary also an attention focused on raising awareness of society about issues involving the universe of children with special needs, in order to promote their inclusion without discrimination, with actions able to awaken to a live with the other, without labels or feelings of regret, but in moderation, different acceptance and solidarity, which also demonstrates the importance of the educational role-professional outreach nurse for the facilitation of this process.

A FAMÍLIA DA CRIANÇA COM NECESSIDADES ESPECIAIS DE SAÚDE: O PROCESSO DE ENFRENTAMENTO E ADAPTAÇÃO

RESUMO

O estudo objetivou conhecer como se dá o processo de enfrentamento e de adaptação da família no cuidado à criança deficiente com necessidades especiais de saúde, a fim de contribuir para a elaboração de possíveis estratégias que facilitem o processo. Pesquisa descritiva de natureza qualitativa, realizada nas Unidades de Saúde da Família de uma cidade no interior da Paraíba. Os dados foram coletados nos meses de Março e Abril de 2012, por meio de entrevista aberta com oito mães de crianças com idade entre 1 ano e 11 meses e 10 anos de idade, com deficiências físicas auditivas e múltiplas com necessidades especiais. Para análise, seguiu-se à metodologia do Discurso do Sujeito Coletivo. As mães demonstraram um difícil e solitário enfrentamento e adaptação à realidade de cuidar de uma criança com necessidades especiais de saúde por não disporem do apoio necessário. Assim, faz-se imprescindível a existência de redes de apoio ao binômio criança-família como subsídio de enfrentamento.

Palavras-chave: Criança. Cuidado da Criança. Família. Enfermagem Pediátrica.

NIÑO FAMILIA CON NECESIDADES ESPECIALES DE SALUD: EL PROCESO DE ENFRENTAMIENTO Y ADAPTACIÓN

RESUMEN

El estudio tuvo como objetivo conocer cómo ocurre el proceso de enfrentamiento y adaptación de la familia en el cuidado al niño discapacitado con necesidades especiales de salud, con el fin de contribuir para la elaboración de posibles estrategias que faciliten el proceso. Investigación descriptiva de naturaleza cualitativa, realizada en las Unidades de Salud de la Familia de una ciudad del interior de Paraíba. Los datos fueron recolectados en los meses de Marzo y Abril de 2012, a través de entrevista abierta con ocho madres de niños con edad entre 1 año y 11 meses y 10 años de edad, con discapacidades físicas auditivas y múltiples con necesidades especiales. Para el análisis, se siguió la metodología del Discurso del Sujeto Colectivo. Las madres demostraron un difícil y solitario enfrentamiento y adaptación a la realidad de cuidar a un niño con necesidades especiales de salud por no disponer del apoyo necesario. De esta manera, es imprescindible la existencia de redes de apoyo al binomio niño-familia como auxilio de enfrentamiento.

Palabras clave: Niño. Cuidado al Niño. Familia. Enfermería Pediátrica.

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Submitted: 13/10/2012
Accepted: 09/10/2013