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RESEARCH

Children with special health needs and family: implications for Nursing

Menores com necessidades especiais de saúde e familiares: implicações para a Enfermagem
Menores con necesidades especiales de salud y familiares: implicancias para la Enfermería

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ABSTRACT

Objective: to understand the family experience of children and adolescents with myelomeningocele by the discovery of chronic illness and their daily life in the realization of needed care to these people. **Method:** qualitative study, developed from October 2013 to February 2014, with family, in a pediatric hospital in Fortaleza. Data were collected through interviews and checked by analysis thematic category. **Results:** it was found that the diagnosis after the birth of the child caused fear and anguish to the families in front of the unknown and the unexpected and that over the years they started to deal with many challenges conducting the daily care due to the disease sequelae. **Conclusion:** nursing plays an important role in the lives of families, children and adolescents, through emotional support, guidelines and care inserted in the health care network.

Key words: Persons with Disabilities; Chronic Disease; Child; Adolescent; Caregivers.

RESUMO

Objetivo: compreender a experiência da família de crianças e adolescentes com mielomeningocele diante da descoberta do adoecimento crônico, bem como sua vivência cotidiana na realização dos cuidados necessários a essas pessoas. **Método:** estudo qualitativo, desenvolvido de outubro de 2013 a fevereiro de 2014, com familiares, em um hospital pediátrico de Fortaleza. Os dados foram coletados por meio de entrevistas em profundidade e verificados por análise categorial temática. **Resultados**: constatou-se que o diagnóstico, após o nascimento do filho, gerou medo e angústia aos familiares perante o desconhecido e o inesperado, e que, ao longo dos anos, eles passaram a lidar com muitos desafios para proceder aos cuidados diários decorrentes de sequelas da doença. **Conclusão**: a Enfermagem assume importante papel na vida dessas famílias, das crianças e dos adolescentes, por meio do suporte emocional, das orientações e dos cuidados inseridos na rede de atenção em saúde.

Descritores: Pessoas com Deficiência; Doença Crônica; Criança; Adolescente; Cuidadores.

RESUMEN

Objetivo: comprender la experiencia de la familia de niños y adolescentes con mielomeningocele ante el descubrimiento de la enfermedad crónica, así como su vivencia cotidiana en la realización de los cuidados necesarios a esas personas. **Método:** estudio cualitativo, desarrollado de octubre de 2013 a febrero de 2014, con familiares, en un hospital pediátrico de Fortaleza. Los datos fueron recogidos por medio de entrevistas en profundidad y verificados por análisis de categoría temática. **Resultados**: se constató que el diagnóstico, después del nacimiento del hijo, generó miedo y angustia a los familiares ante lo desconocido y lo inesperado, y que, a lo largo de los años, ellos pasaron a lidiar con muchos desafíos para proceder a los cuidados diarios decurrentes de secuelas de la enfermedad. **Conclusión**: la Enfermería asume un importante papel en la vida de esas familias, de los niños y de los adolescentes, por medio del soporte emocional, de las orientaciones y de los cuidados inseridos en la red de atención en salud.

Palabras clave: Personas con Deficiencia; Enfermedad Crónica; Niños; Adolescente; Cuidadores.

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INTRODUCTION

Children and adolescents with special health needs are those who are at higher risk of having physical, behavioral, development or emotional chronic(1). Currently, these people represent a new customer profile with diverse health needs, especially concerning specialized services to meet their demands and qualified multidisciplinary team, providing interdisciplinary care for them and their families(2).

In the global context, neural tube defects have an incidence ranging between 0.79 to 6.39 per thousand live births(3). The second edition of the World Atlas of Birth Defects, elaborated by the World Health Organization (WHO) showed variable data of neural tube defects in several countries in the period 1993 to 1998. In Brazil, the statistics were collected in 11 maternity hospitals, through the Latin American Collaborative Study of Congenital Malformations (ECLAMC). According to this study, Brazil is in fourth place in the prevalence of *spina bifida* among the surveyed countries(4). The survey of 2001 showed ECLAMC rate of 3.3 per thousand live births in Brazil, the largest among the five assessed countries(5).

Among these neural tube malformation, myelomeningocele represents approximately 75% of cases. It is considered the most severe form because it consists of a cystic protrusion that contains nervous tissue unprotected by the skin, exposed to the environment, and, consequently, causing severe complications such as neurological disorders, physical deformities, sensitivity déficit, dysfunction of the urinary tract and bowel function(3,6).

Because of these sequels, children and adolescents with myelomeningocele will require greater attention and care to their families, and face several challenges in carrying out their daily activities, mainly due to limited mobility and the presence of fecal and urinary incontinence. These conditions impose the need for some home procedures such as intermittent bladder catheterization and use of locomotor support equipment(6-7).

According to the World Health Organization (WHO), chronic diseases are the leading causes of death and disability in the world. Are defined as those with long permanence, slow evolution, normally recurrent and thus contribute to the suffering of individuals, families and society, requiring continuous attention and efforts of a set of equipment and public policies(8). The myelomeningocele is considered a chronic disease because it requires their carriers an uninterrupted treatment, prolonged professional care and frequent hospitalizations(9).

From this perspective, nursing plays an important role in the care of these people, through reception and support to the families from birth to the time of hospital discharge and subsequent follow-ups, helping them to deal with this process of change before the arrival of a newborn with this chronic disease. Thus, the nurse needs to be able to provide coordinated assistance under the Health Care Network, in a comprehensive and humane way, including the impact of this malformation in the context of the life of these families(10).

It is, therefore, imperative the need to develop studies aimed at the further development not only of relevant knowledge about clinical aspects of the disease but that address the various dimensions of living with this chronic condition. Thus, there will be the possibility of further discussion about the issue and a subsequent improvement and/or creating strategies that enhance their health care from a public service that considers the universe in which these users live with their specificities and everyday needs.

Given the above, this research aimed to understand the family experience of children and adolescents with myelomeningocele in front of the discovery of chronic illness and their daily life in the realization of care to these people.

METHOD

It is a qualitative study, exploratory, performed at a tertiary pediatric public hospital with reference in the state of Ceará. In this institution, children and adolescents with myelomeningocele are accompanied by Specialties Clinic, which offers different services for users under 18 years with special health care needs, including allergy services, gastroenterology, neurology, pulmonology, ophthalmology, gynecology, rheumatology, pediatric surgery, pediatrics, nephrology, psychology, nutrition, odontology, neurology pediatric, urology, genetics and endocrinology.

15 relatives participated in this research responsible for children/adolescents with myelomeningocele. It sought to explore, in depth, the perspective of the participants to understand and interpret their realities and thereby obtain certain saturation of the treated subjects(11). Inclusion criteria were: responsible relative must be present during follow-up and treatment in the hospital; they must be the usual escort during health services to share information with more details about the object under study, and present availability of time to participate in the research. They excluded, among those responsible, those with a mental deficit that harm their participation in interviews and had little knowledge of the child's or adolescent's daily life.

Data collection occurred from October 2013 to February 2014. A depth interview with two items was used, the first, characterization of the child/adolescent and accompanying family member, and the second composed of the following guiding questions: talk about your experience with the birth of a newborn with special health care needs and your daily life to take care of children/adolescents with myelomeningocele. All interviews were conducted, recorded and transcribed only by the researchers.

The theory of Jean Watson was used as the theoretical framework, whereby the main focus of nursing lies in the care factors that represent the essence of nursing. According to theory, care can help a person to gain control, become knowledgeable and promote health changes. There is a high regard for the autonomy and freedom of choice, giving emphasis to self-knowledge, self-control, and the customer as the responsible person(12).

In his work, Watson also highlights the need that care transcends the biophysical sphere, involving a satisfactory attention to the soul, taking into account the family, cultural and community context in which the patient is inserted. Thus, the author proposes needs orders that need to be understood so that care occurs in the best possible way: lower order needs (biophysical and psychophysical) and higher-order needs (psychosocial and intrapersonal)(12). With these assumptions, the findings were interpreted as a means of generating information that contributed to the nursing care provided to children and adolescents with myelomeningocele and their families, based on the presentation of a global overview that reveals the challenges and daily lives of these people.

To analyze the findings, we followed the steps recommended by the categorical thematic analysis of Bardin(13), which recommends dismemberment operations of a text in units and categories, according to analog groupings. Among the different ways of categorizing, the investigation using subjects is considered effective and faster in the case of simple and direct addresses. The steps were: pre-analysis, material exploration, treatment of results, inference and interpretation.

In pre-analysis, there was a fluctuating reading of findings and initial appropriation of content, with subsequent selection of the most relevant parts of the objective of the research for the establishment of the working *corpus*, through the representativeness criteria, homogeneity, and relevance. At the end of this stage, the selected data were edited for analysis. The second stage was permeated by decomposition operations, aimed at defining categories through the cutout of the nucleus of meaning in the words of the participants, which gave meaning to the aspects analyzed in the study. Thus, the transcripts contained italics highlighting relevant parts of the study, subsequently copied to another file.

In the last step, the selected data received treatment to be valid and meaningful. Thus, inferences and interpretations were performed to highlight the main information found in the research and expose them clearly(13). After the final analysis, with the development of the central themes, the following thematic categories were synthesized, according to Bardin, presented the mutual exclusion characteristics, homogeneity, relevance, objectivity, fidelity and productivity: 1- Facing the new and the unknown and 2- Caring special health care needs people.

It is noteworthy that the research was approved by the Research Ethics Committee of the cited hospital and had the consent of the Specialties Clinic management. Moreover, all the rules of Resolution No. 466/12 of the National Health Council were followed. Next, some precautions were taken to protect the identity of participants, replacing their real names by other fictitious.

RESULTS

Characterization of the participants, children, and adolescents with myelomeningocele

Of the 15 responsible, 14 were mothers and one was the father, with a predominance of participants aged between 30 and 40 years (10). Regarding the level of education, more than half had only attended Elementary School Incomplete (9); one responsible, Elementary School Complete; other three attended High School; one person was illiterate, and another one had attended the Higher Education Complete. Regarding marital status, most of them were married or living in stable relationships (11). There was a predominance of people who did not exercise formal work activities, performing home services only. Regarding the number of children and the position of the child or adolescent with chronic illness, 12 had more than one child, and nine with myelomeningocele were among the youngest. About the provenance, almost all participants resided in inland municipalities of the state (13). The average income of the families was between one and two minimum wages, especially the Continuous Cash Benefit (BPC), received by families of one minimum wage.

Concerning children and adolescents, ages ranged from three months to 13 years and of these, nine were in the mandatory age for enrollment in educational teaching, but only six frequent school. Concerning the complications of their illness, there was a high prevalence of children and adolescents with urinary and/or fecal incontinence and sequelae related to locomotion. Four had not yet been diagnosed as the changes due to age; eight did not walk, and three had a non-functional gait, i.e., locomote with difficulty, needing a wheelchair or other media to meet their needs.

Facing the new and the unknown

For most families, the discovery of myelomeningocele occurred only after delivery of the newborn, despite the mothers, when pregnant, have made a full follow-up on prenatal, performing during this period, ultrasound exams to monitor growth and fetal formation.

> *In my pregnancy, I did three ultrasound, but did not enough to discover; it happened, they did not tell me because the first ultrasound that I did she was on her back, and they did not say anything.* (Léa)

> *I did prenatal with nine months but was only discovered when she was born.* (Penha)

In this context, it is observed that the child's birth resulted in some families, great surprise, and commotion for dealing with the unknown, the new and the different, especially when the mother had gestated "normal" children without congenital abnormalities.

> *It's a different experience, very different because I have two children, and they are normal, born normal. At the very day she was born, it was different because they took her to a room. When the anesthesia finished, they put me in the recovery bed, she was not with me, I found strange because I did not know what myelomeningocele was, I did not know. Till today, I discovered because of this situation, I did not know and had no idea what it was.* (Mara)

All newborns were sent to referral hospitals in larger cities to perform the myelomeningocele repairing surgery. In this context, some respondents revealed through sadness and crying, suffering faced during the period that followed the hospitalization of the child before and after surgery. These feelings were accentuated with the separation and missing of the other children who stayed at home and with the hard news about the sequelae of myelomeningocele and operative risks, announced by health professionals in a dehumanized way.

> *When he was born, he had a lump, and when he came [to the pediatric hospital of reference] he operated. Then the doctor said, "or he dies or he will be crippled". I said, "ii*

> *will be what God wants, being crippled or not, I want him good." He was very tiny; you could imagine he would not escape. He was operated, I spent a month with him here in the hospital, suffering with him, I cried day and night remembering the others because, at that time, others were small as well.* (Rebeca)

After hospital discharge, the arrival of the child at home generated big changes in the family routine, which had to restructure its organization to provide all necessary care and continuous for the child, challenging situation for its members, who expressed feelings of fear and insecurity in front of the chronic illness. The new situation was an everyday learning as follows speech reveals:

> *It was not easy for me, because we did not expect he was born that way, but gradually, we will learn, every day, for being alive with us. But I can not say it was easy in the first days, first months, first years, it was too difficult. We did not have the knowledge; the first child has experience of nothing but with God's grace, we are with him here telling the story.* (Ezequias)

Caring for people with special health needs

The way as families deal with the arrival of the child at home and the need for continuing care were variables aspects among respondents. For some, there was no strangeness in front of the deficiencies and the resulting dependencies in daily activities. However, for most, taking care of a child/adolescent with special health care needs generating fear, mainly due to little knowledge about the disease, treatment, and sequelae.

> *For me it is normal since she was born I take care of her, for me it's already normal, I never rejected* [...]. (Rafaela)

> [...] *I'm afraid to take care of him because he is a special child, different from the others.* (Esequias)

The routine of the family, especially the mother, being the main caregiver, was reorganized on new responsibilities and constant demands. Most often, these caregivers have moved away from their activities outside the home to stay home with the children, giving them all the necessary attention, with the care of body and oral hygiene, feeding, diaper and dress, as shown in the statements:

> *I have to do everything, bath* [...] *sometimes he says "Mom, I'm all dirty", then I caught, and I wash him, I change diapers, clean him when he poops. I take care him well.* (Rebeca)

> *She uses disposable diaper, I bath her, took from the chair, put her on the bed, then tidy when she is at school, I put her on the seat again, I make lunch, I put cologne, brush her, brush her teeth, I comb her hair, because everything has to be myself.* (Naomi)

As a consequence of urinary incontinence, most need the Bladder Sounding for Relief (BSR) at home, requiring great commitment from the caregiver and responsibility as the demands on the schedules previously established for its completion, which generated different feelings and expectations in caregivers, as express the lines:

> *I've been guided to make* [BSR], *but I have not courage* [...] *it was the people of the hospital, it was passed by the doctor.* (Naomi)

> *Caution is redoubled because recently, she did a treatment at P Hospital, there it is said that she has to take the medicine and do the catheterization* [BSR] *five times a day, which is put probe.* (Lidia)

Besides these activities, the caregiver still needed to be available to travel frequently with the children and adolescents to health services. Some difficulties reported by mothers because of this routine mainly were related to weight and size of children and adolescents, making care difficult over the years, especially because they have to carry them in their arms in most activities and visits to health services and other necessary places, like school.

> *She is my life; I wonder if this had not happened to me* [labor license for a tumor in the throat] *because she lives in the hospital. It is very hard working and caring.* (Jane)

> [All] *on the arm* [...] *a loto f weight, it's hard. Not everyone can take her. I have to bring her to school and because not everyone can do it.* (Samara)

The difficulty of access to school is also emphasized due to the need for a BSR (being necessary, in some cases, the presence of a caregiver in this educational environment) and issues of organizational nature of these sectors, poorly prepared structural and humanely to accommodate children and adolescents with special health care needs, as verbalized by some participants.

DISCUSSION

The findings of this research for the diagnosis of myelomeningocele corroborate the literature to show that a high rate of pregnant women has not received the diagnosis during the pregnancy period, or it was informed only at the end of pregnancy(14). It is noteworthy that although ultrasound is a widely performed procedure during pregnancy, including the public health system, the identification of myelomeningocele depend on a number of factors, including the fetal position, device quality and experience of health professionals in carrying out and interpreting the test, factors that may also be associated with the frequency of late diagnosis(15).

When dealing with the news of chronic illness, family members have experienced traumatic situations, with feelings of anguish and shock at the unexpected. In this sense, inadequate communication between health professionals and parents, the omission of information, and the lack of emotional support and enlightenment about the illness and treatment, were found in the reports of caregivers, revealing the lack of preparation of the health team to deal in a humane way with both the mother and child.

These issues corroborate other research, which found that health professionals have been little prepared to provide information about the diagnosis of children with congenital abnormalities, which expresses the existence of failures in health education. However, the family feels the need to hear explanations by health professionals, because many questions raise at the birth moment. The consequence of the lack of training of these professionals can directly interfere with parents relationship with the newborn and generating distorted expectations concerning illness and thereby influence the rejection process or acceptance of the child(16).

In fact, mothers need to be informed both about the illness of their children as the procedures that will be submitted. However, frequently, the information provided by members of the health team are not adequately understood, and sometimes, the guidance does not even occur because the professionals worry much with the completion of technical procedures, away from the appropriate posture to a humanized care(17).

This study shows similar results according to Guerini and other authors allege, in which the families of children with special health care needs to be reported that, after birth and discovery of the child's illness and their need for ongoing care, their lives changed a lot. However, they believed that the effort was valid to promote a better quality of life to their children(18).

The family is faced with major challenges to overcome their fears and lack of preparation before the congenital change news on their son, learning, over time, to live with the new, the different and deal with the prejudices of a society that labels the people with disabilities(19). The family experience of this care revealed by the search for greater understanding of the health problem, its causes and long-term effects, as well as feelings of insecurity and distrust. Thus, the hospital discharge is seen as something remarkable in the lives of family members, for being the beginning of a learning way and new appropriations about care(20).

The home structure has suffered reorganization to welcome the new member, being common, as shown by other studies, that mother is the main caregiver, deviating from their work activities to dispense all of the necessary continuing care(10,21-22). From this perspective, disease and caregiver practice transcend the individual sphere of the person with chronic illness and reach all members of the family, especially the primary caregiver. Thus, it is a common appreciation of expressions of mothers who feel overwhelmed with so many responsibilities and functions, based on the child with special health needs(20).

Even considering the feasibility of correcting the myelomeningocele, complications are permanent and will vary according to the length and height of spinal injury and exposure time and quick surgical procedure. However, the use of braces and other devices can ease the difficulties arising from these disorders, though still required great efforts for children, adolescentes, and their families, especially in the growth phase and child development, which will require time and constant adaptation(9).

Cipriano and Queiroz also observed similar features in their data. According to them, the mothers of children with myelomeningocele have expressed difficulties in caring for their children, by using all their time to meet the required demands, providing them with nutritional care, hygiene care, stimulus to its development, among others(6).

The lack of vesical sphincter control is also mentioned in the literature as well prevalent among people with myelomeningocele(6,9,23-24), which leads to the need to use diapers, and children and adolescents, because they depend on their parents to carry out the change and hygiene, can, under certain circumstances, have to stay with the same diaper long periods, which compromises their hygiene(25).

In many cases, urinary incontinence becomes necessary to perform the BSR with the function of preventing the occurrence of complications such as urinary infections related to incomplete emptying of the bladder and kidney problems, besides being an alternative to controlling incontinence(14,22,26).

Confirming our findings, study that investigated the perceptions and feelings of family caregivers about achieving BSR in children with myelomeningocele demonstrated the use of expressions of positive and negative connotations about this procedure. The negative connotation has been expressed by words such as fear, evil, complicated and difficult while performing the technique with children(22).

Thus, it is believed that during the training, must be clarified doubts and worked the fear of caregivers before the procedure, guiding them about their importance to children and adolescents, allowing them opportunities to realize it yet in the hospital, when they feel ready.

Thus, under those situations and frequent sequelae, family members need to be guided by the health team also for the realization of the other home procedures after discharge, such as: administering medication, accident prevention, and skin lesions due to the reduced sensitivity of the lower limbs, beware orthotics, assistance with feeding, hygiene and transportation, among others.

Another current challenge in daily life concerns access to school because there is a need for this to present an adapted structure to people with disabilities and enlist qualified educators to receive them. It is also necessary to create effective public policies and be effectively implemented to the existing ones, so that these people receive a quality education, with the guarantee of access and permanence in the educational context(25).

In this sense, it is emphasized that according to the Guidelines and Bases of National Education, specialized educational services to people from 4 to 17 years old with disabilities should be free and settled preferentially in the regular school system(27). Even though, it reinforces that according to the National Plan for the Rights of Disabilities Persons, inclusive education should be guaranteed for persons with disabilities, through free educational equipment available to them(28).

Regarding the need for treatment, rehabilitation and health monitoring in the different levels of care of children and adolescents with myelomeningocele, it is noted that it is a right of all Brazilians, regardless of their genetic characteristics, socioeconomic conditions, and to live or not with any pathology or disability, to receive welcoming health care and free from any kind of discrimination, aimed at the promotion of a quality equal treatment for all and respect for its uniqueness(29).

However, it is emphasized that the locomotor sequels still generate more work overload for carers, especially because they live in the inland of the state, far from specialized services, which hinders access to health services. For these reasons, the treatment of children and adolescents has been compromised, according to some relatives, with a need to be discussed between managers, public authorities, health professionals and users, strategies for these people to have, in fact, their effective right to quality and continuous health service.

In this context of daily care and demands in health, taking into account the low socioeconomic status of participants, it emphasizes the importance of BPC as of vital importance for the families supply. It is a guaranteed benefit through Decree No. 6214, set up in 2007 to the disabled and elderly older than 65 years old, proving that do not have any income to provide their livelihood and not have it provided by their family(30).

Therefore, the daily lives of these families are permeated by challenges in the appropriation of these rights, in the learning through the care of children and adolescents with special health care needs, in the search for affordable health care and quality and the fight for social inclusion. These challenges become even greater in the middle of a society that discriminates against people with disabilities and offer few possibilities, often restricting their real potential.

CONCLUSION

The child and adolescent illness news after birth are a difficult and unexpected process for families, which creates pain and suffering, especially when the relationship with health professionals does not occur satisfactorily. In such cases is generated more anguish when parents, for not knowing what will happen to their children, feel deprived of emotional support and proper communication with the health team.

After hospital discharge, families restructure to welcome the new member, who will depend on their continuing care as a result of the sequelae of myelomeningocele, usually being the mother the principal responsible. She is who gives up their activities and work to meet all the child's needs with chronic illness, accompanying them on frequent searches and treatments in health care and struggling in the face of adversity, to provide the best quality of life.

From the results of this research and observation about the experience of these people, it highlights the importance of nursing rethink their actions in pursuit of development and more active participation in health teams, which means welcome families and children/adolescents with special health care needs throughout the care network. Therefore, it is necessary to empower caregivers about the home activities, guiding them regarding the performance of procedures for bladder emptying and prevention of skin lesions, developing activities that encourage autonomy and independence of children and adolescents, providing them information about their rights and how to proceed to achieve them. It is also important that the team clarify any doubts about the chronic illness, as well as provide emotional support and family care, which should also be the focus of their attention.

The research has limitations, listening only the family members of children and adolescents with myelomeningocele. I could have had greater breadth and depth of results if there was also the participation of nurses and other health professionals who provide assistance to these people. However, for the purpose of this investigation, the goal has been achieved, noting that the findings do not end here, as there is need for further discussions on the subject, as well as developing new studies to include other facets, to contribute to improving the quality of life of this segment of the population.

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