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INTEGRATIVE REVIEW ARTICLE

CARE FOR FAMILIES OF CHILDREN WITH CHRONIC DISEASE

CUIDADO À FAMÍLIA DA CRIANÇA COM DOENÇA CRÔNICA

CUIDADO A LA FAMILIA DEL NIÑO CON ENFERMEDADES CRÓNICA

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ABSTRACT

Objective: to know what has been produced about the care provided for families of children with chronic disease. ***Method:*** integrative review that sought to survey the publications of the last 10 years in the MEDLINE, LILACS, BDENF, INDEX PSICOL databases and in the virtual library SciELO. After reading the selected articles, we analyzed data of the studies regarding authorship, objectives, year of publication, method and level of evidence. ***Results:*** the findings led to two thematic categories << Facing the diagnosis of a chronic disease, change of habits and family reorganization >> and << Care routines of families with children with chronic conditions >>. ***Conclusion:*** Families of children with chronic diseases have their routines modified, often losing control over their lives. We believe that if families are well informed about the pathology and if they are empowered to care for the child, they will be able to develop autonomy over the organization of their lives. ***Descriptors***: Family; Child; Chronic disease; Empathy; Pediatric Nursing; Review.

RESUMO

Objetivo: conhecer o que vem sendo produzido sobre o cuidado à família da criança com doença crônica. ***Método:*** revisão integrativa que buscou conhecer as publicações dos últimos 10 anos nas bases de dados MEDLINE, LILACS, BDENF, INDEX PSICOL e na biblioteca virtual SciELO. Após a leitura dos artigos selecionados, foram analisados os dados dos estudos referentes à autoria, objetivos, ano de publicação, método e nível de evidência. ***Resultados:*** com base nos achados, foram definidas duas categorias temáticas << Enfrentando o diagnóstico da doença crônica, mudança de hábitos e reorganização familiar >> e << Rotinas de cuidado das famílias com crianças com condição crônica >>. ***Conclusão:*** as famílias das crianças com doença crônica são afastadas de suas rotinas, muitas vezes, perdendo o controle sobre suas vidas. Acredita-se que se a família for bem informada sobre a patologia e empoderada para os cuidados à criança, esta poderá desenvolver autonomia sobre a organização da sua vida. ***Descritores:*** Família; Criança; Doença Crônica; Empatia; Enfermagem Pediátrica; Revisão.

RESUMEN

Objetivo: conocer lo que viene siendo producido sobre el cuidado a la familia del niño con enfermedad crónica. **Método**: revisión integradora que buscó conocer las publicaciones de los últimos 10 años en las bases de datos MEDLINE, LILACS, BDENF, INDEX PSICOL y en la biblioteca virtual SciELO. Después de la lectura de los artículos seleccionados, fueron analizados los datos de los estudios referentes a la autoría, objetivos, año de publicación, método y nivel de evidencia. **Resultados**: con base en los hallados, fueron definidas dos categorías temáticas << Enfrentando el diagnóstico de la enfermedad crónica, cambio de hábitos y reorganización familiar >> y << Rutinas de cuidado de las familias con niños con condición crónica >>. **Conclusión**: las familias de los niños con enfermedades crónica son alejados de sus rutinas, muchas veces, perdiendo el control sobre sus vidas. Se cree que si la familia fuera bien informada sobre la patología y empoderada para los cuidados al niño, esta podrá desarrollar autonomía sobre la organización de su vida. ***Descriptores***: Familia; Niño; Enfermedad Crónica; Empatía; Enfermería Pediátrica; Revisión.

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INTRODUCTION

When parents receive the news of the diagnosis and prognosis of a chronic disease of their children, they initially experience a moment of shock.[1] Such discovery represents an event of strong emotional impact, and consequently of sadness and anxiety due to the fear of the unknown. Families often do not feel prepared to face the situation.[2] However, they gradually begin to accept and adaptat to the new condition of their child.[1]

Chronic health conditions consist of situations that require continuous and permanent care.[3] These conditions are those of long course, and can be incurable, bring sequels, require continuous care and impose limitations on human functions, thus requiring adaptations.[4]

Being affected by a case of chronic disease represents an intense and complex experience that generates conflicts, feelings and difficulties in dealing with the unpredictability of the new condition of the child. From this perspective, care becomes prolonged and often painful, requiring permanent care in relation to therapy and factors that may aggravate the health state of the child.[5] Once the diagnosis and prognosis are established, the adaptation of the families to their new condition is fundamental for them to take care of the affected child, meeting all the child's needs.

Parental care and love offer children the ability to develop their human potential to manifest their own way of being in the world,[6] however, each family will deal with the new situation in a singular way and this will depend on the previous experiences, beliefs, values of each family member, and the influence and space they develop and occupy in their organizational network.[1]

The experience of facing a chronic disease in childhood generates demands for care to the families, as well as changes in their routines. They start to live under strong anxiety for being responsible for the sick child who now depend on continuous attention, care with food, drug treatment, besides the constant concern with their clinical state, which imposes on families overload and suffering.[7] Caring for children who live with a chronic disease necessarily implies considering them from the perspective of their connection with the figure of the mother, father and/or caregivers, in that the well-being of one directly affects the condition of the other, because the care advances according to the orientation and involvement of the family in this process.[8]

OBJECTIVE

- To know what has been produced about the care of families of children with chronic diseases.

MÉTHOD

Integrative review that sought to identify the theme and the question of the research in published articles, based on previously defined inclusion and exclusion criteria. A synthesis of the articles was carried out by defining the information and interpreting the results.[9]

The steps to carry out the research were as follows: elaboration of the theme and question to be explored in the research; establishment of inclusion and exclusion criteria of studies; definition of the information to be collected from the selected studies; evaluation of the studies included in the integrative review; interpretation of results; presentation of the review, synthesis of knowledge.[9]

This trajectory was followed in the expectation of answering the question that guided the study: "What has been produced about care provided for families of children with chronic diseases?"

The databases used for the search were the Medical Literature, Analysis, and Retrieval System Online (MEDLINE), Latin American and Caribbean Health Sciences Literature (LILACS), Nursing Database (BDENF), Index of Technical Scientific Psychology Periodicals (INDEX PSICOL) and the *Scientific Electronic Library Online* (SCIELO). Data were collected in February and March 2017 using the following descriptors: *Child; Chronic disease; Care; Family*. All descriptors were connected by the boolean operator "and".

Regarding the inclusion and exclusion criteria of studies, the following were included: original studies with qualitative and quantitative methodologies published in the last 10 years, in Portuguese, English and Spanish, and that met the research objective. Abstracts of communications in conventions, news, letters to the editor and duplicated studies were excluded.

Data was collected by three reviewers and a fourth reviewer was consulted in case of doubts. A proper instrument was prepared for data collection, including the following information: authors, year of publication, design, level of evidence, population and main results.

The application of the descriptors resulted in 2888 articles. The refinement of the search according to the inclusion and exclusion criteria left 985 articles remaining. Thirty-nine articles approached the theme under study, of which 20 were from the Medical Literature, Analysis, and Retrieval System Online (MEDLINE); six from the Latin American and Caribbean Health Sciences Literature (LILACS); two from the Nursing Database (BDENF); one of the Index of Technical Scientific Psychology Periodicals (INDEX PSICOL); and 10 from the Scientific Electronic Library Online (SCIELO).

After reading the selected articles, we analyzed the data of the studies regarding authorship, objectives, year of publication, method and level of evidence. The level of evidence was evaluated according to Figure 1.[10]

Level of evidence	Type of study
I	Systematic review and meta-synthesis
II	Randomized or controlled trials
III	Controlled trials without randomization
IV	Cohort or case-control study
V	Systematic review of qualitative or descriptive studies
VI	Qualitative or descriptive studies
VII	Opinion of authorities or expert committees

Figure 1. Classification of level of evidence. Pelotas (RS), Brazil, 2017.

The accomplishment of this study respected the theme approached and the content of the articles used with no distortion of content and/or plagiarism. According to Copyright, Law Nº 9,610 of February 1, 1998.[11]

RESULTS

After reading the selected studies, a characterization of the studies was done, as presented in Figure 2. Then, the data were examined as to whether they responded the research question and the results were then categorized and interpreted.[9]

Authors/Year	Objective	Type of study	Level of evidence
Figueiredo; Sousa; Gomes/ 2016[12]	To understand the experience of families of children and adolescents with myelomeningocele in the face of the discovery of the chronic disease, as well as their daily experience in providing the necessary care for these affected individuals.	Qualitative	VI
Pereira et al./ 2014[13]	To analyze care provided by mothers caring for children with cerebral palsy, considering their own way of being, their origin and purpose.	Qualitative	VI
Leal et al./ 2009[14]	To describe the coping of the disease by the relatives of type 1 diabetes mellitus patients and to discuss the importance of these relatives in the control and treatment of the disease.	Qualitative	VI
Hill; Baird; Walters / 2014[15]	To use qualitative interviews with children, parents and health professionals to identify the impacts on the quality of life and well-being of children and their families.	Qualitative	VI
Goldschneider et al. / 2014[16]	To provide to users information about pain care for children and adults with epidermolysis bullosa.	Systematic review of qualitative studies	V
Guffon et al. / 2015[17]	To evaluate the burden of mucopolysaccharose on patients, families, on the health system and social services in France.	Controlled trial	III
Creary et al. / 2015[18]	To explore what impacts the decision of caregivers to accept or decline hydroxyurea (hu) therapy for their children with sickle cell disease.	Qualitative	VI
Rocha et al. / 2015[19]	To know the care routines of families of cerebral palsy children.	Qualitative	VI
Sousa et al. / 2012[20]	To investigate the self-care requirements in health deviations associated with chronic kidney disease in children and adolescents, identify the nursing diagnoses in self-care deficits and develop interventions with the child/adolescent at the moment of identifying the deficits in self-care requirements.	Qualitative	VI
Freitas et al. / 2011[21]	To develop a proposal of care for family members of children with chronic kidney disease based on the difficulties faced at home using as theoretical reference the Basic Human Needs and the International Classification for Nursing Practice to	Qualitative	VI

	name nursing diagnoses and interventions.		
Tunde-ayinmode / 2015[22]	To describe the psychosocial profile of a group of children assisted in clinics for the treatment of bronchial asthma in order to understand the frequency and nature of these problems so that the intervention program can be designed and implemented.	Qualitative	III
Swallow et al. / 2014[23]	To report on one aspect of a study of interactions between professionals and parents in a network of 12 kidney units for children in Britain.	Qualitative	VI
Sobotka; Francis; Booth / 2015[24]	To describe the experiences of parents with specific components of the medical home for their children with autism spectrum disorder.	Qualitative	III
Berlinski et al. / 2013[25]	The Arkansas Children's Hospital began a work on quality improvement with the goal of increasing the percentage of patients assisted four or more times per year from 35% in 2004 and 56% in 2005 (Cystic Fibrosis Foundation Registry Data) to 90% or more.	Controlled trial without randomization	III
Brinkman; Epstein / 2011[26]	To analyze the recommended physician-parent interactions, examine the current practice patterns and identify the facilitators and barriers to the implementation of practices for care for Attention Deficit Disorder.	Qualitative	I
Grossoehme; Cotton; Mcphail / 2013[27]	To understand the perspectives of parents on using various modalities of complementary and alternative medicine to help their children with Cystic Fibrosis.	Qualitative	VI
SATO et al. / 2013[28]	To explore the differences between ethnic/racial groups as for the quality of the home environment (global and specific) among white, Latino, non-Latin and African-American children with asthma; to examine the associations between quality and quantity of support and stimulation in the domestic environment.	Qualitative	VI
Franciosi et al. / 2012[29]	To identify the main reported patients and parents for Eosinophilic Esophagitis disease.	Qualitative	VI
Eichenfield et al. / 2014[30]	To discuss the methods for diagnosis and monitoring of diseases, measures of results for evaluation and common clinical associations affecting patients with atopic dermatitis.	Systematic review	I
Nadkarni; Fristad / 2012[31]	To report the stress related to the parenting of a young boy with bipolar disorder, maladaptive adaptation, and immunological and physical functioning related to chronic stress.	Controlled trial	III
Ouyang et al. / 2014[32]	To investigate the functional limitations of children with Fragile X syndrome with Intellectual Disability and/or Autistic Spectrum Disorder, the occurrence of aggravating factors related to genetic diseases, including the economic and employment impact on families.	Qualitative	VI
Amzel et al. / 2013[33]	To explore the negative effect of various HIV-specific factors on the psychosocial well-being of HIV-infected children: disclosure, stigma and discrimination, and death, in order to increase self-confidence and self-acceptance among children and their caregivers and to promote self-care.	Controlled trial	III
Oliver-Carpenter et al. / 2011[34]	To examine the level of involvement in disease management tasks of young people with sickle cell disease and their caregivers.	Controlled trial	III
Schiariti et al. / 2014[35]	To identify important strong points and limitations for children with cerebral palsy through self-report of children or caregivers. To describe contextual factors influencing these limitations, either positively or negatively. To compare the agreement and disagreement between the self-report of children and caregivers.	Qualitative	VI
Andrade; Vieira; Dupas / 2011[36]	To understand the experience of the family with the cerebral palsy of the child, to identify the changes that this chronic condition causes in family life and what are the coping mechanisms used.	Qualitative	VI
Pizzignaco; Mello; LimA / 2010[37]	To understand the experience of Cystic Fibrosis based on the family context.	Qualitative	VI

Volpini et al. / 2013[38]	To understand the parents' perception of children with Cerebral Palsy about the use of wheelchairs in the daily life of their children.	Qualitative	VI
Holanda; CollET / 2011[39]	To understand the perception of the families of hospitalized children with chronic diseases regarding the distance from the schooling process.	Qualitative	VI
Okido et al. / 2016[40]	To understand the experience of mothers with the care of children who depend on technology for drug therapy.	Qualitative	VI
Okido et al. / 2012[41]	To understand the experience of mothers with the care of children who depend on technology.	Qualitative	VI
Pedroso; MotTA / 2013[42]	To know the perceptions of family members of children living with chronic diseases on components of situations of vulnerability, relating them to the Socio-Ecological Theory.	Qualitative	VI
Ribeiro; Rocha / 2007[43]	To understand the care provided for children with Nephrotic Syndrome, identifying new contextual elements and horizons to reconstruct nursing care, focusing on the family.	Qualitative	VI
Holanda; CollET / 2012[44]	To investigate the meaning of the experience of the educational process of hospitalized children with chronic diseases from the family's perspective.	Qualitative	IV
Silva et al. / 2015[45]	To understand the action/interaction strategies adopted by the nursing team to care for hospitalized children with chronic conditions.	Qualitative	IV
Rodrigues et al. / 2013[46]	To investigate the interaction between the nursing team and the families of hospitalized children with chronic diseases, from the parents' perspective	Qualitative	IV
Silva; Silva; Leite / 2016[47]	To understand the intervening conditions to the interactions of nurses in the management of nursing care for hospitalized children with chronic conditions.	Qualitative	IV
Barbosa; Sousa; Leite / 2015[48]	To unveil the intervening conditions for the care of children with chronic conditions.	Qualitative	IV
Webb et al. / 2011[49]	To evaluate the factors associated with the time taken to access the specialists and explore the issues experienced by parents before evaluation in a specialized service.	Qualitative	IV
Fidika; Salewski; Goldbeck / 2013[50]	To evaluate the quality of life of parents of children and adolescents with phenylketonuria.	Qualitative	IV

Figure 2. Identification and objectives of the selected studies. Pelotas (RS), Brazil, 2017.

As for the year of publication, there was one (2.57%) article published in the years 2007[43], 2009[14] and 2010[37], three (7.69%) articles published in the year 2016[12,40,47], five (12.82%) in 2012[20,29,31,41,44], six (15,38%) in 2011[21,26,34,36,39,49] seven (17,95%) in 2015[17-9,22,24,45,48] and 2014[13,15-6,23,30,32,35] and eight (20,51%) in 2013[25,27-8,33,38,42,46,50].

Regarding the object of the studies, 11 (28.20%) articles focused on the family[12,14,19,21,31,36-7,39,42-4], three (7,69%) on the mothers[13,40-1], one (2.57%) on the children, parents and health professionals[15], seven (17.95%) studies dealt with children[16,20,22,25,28,34,48], four (10,26 %) with children and their families[17,32-3,35], six (15,38%) studies focused on parents (mother and father)[18,24,27,38,49-50], two (5,12%) studies on parents and health professionals[23,26], one (2.57%) on the child and the parents[29], one (2.57%) on the health professionals[30], two (5.12%) on the nursing professionals,[45,47] and, finally, one (2.57%) focused on the nursing professionals and the family.[46]

A synthesis of the results found in the articles gave origin to two thematic categories: Facing the diagnosis of a chronic disease, change of habits and family reorganization; Care routines of families with children with chronic conditions.

DISCUSSION

♦ Facing the diagnosis of a chronic disease, change of habits and family reorganization

The diagnosis of a chronic condition in childhood causes in some families a great surprise and emotional shock, because it is something new, unknown and different, especially when families are unaware of cases of children with such chronic diseases.[12] Thus, the family has to adapt to the health state in which their children are now, because when they fall ill they are inserted in a world of commitments and daily habits, which until now were not known by the family, constituting a long, difficult and unpredictable course and requiring the adaptation of the whole family routine to make it possible to care for the children, with a new health condition.[21]

A chronic condition in children generates major changes in the daily life of the families. The family must restructure its organization and provide the necessary and continuous care to the children. This situation challenges family members, who end up expressing feelings of fear and insecurity about the childhood illness and the diagnosis of the chronic condition.[12]

There are changes in the habits of the parents related to the preoccupation with the feeding of the children who, in some cases, cannot eat the same as the other members of the family, thus generating changes in the diet of the whole family group. Another change concerns family sleep, which is also disrupted due to the ongoing care needed.[29-30]

Parents of children with chronic illness face many difficulties, such as less interaction with friends and relatives due to the continued care for their children. In addition, there is also the financial tension related to treatment expenses and the emotional and physical health of the caregivers, which is usually neglected.[31]

Family life arrangements are reorganized in terms of work, with reassignment of working hours in order to meet the children's care, change of jobs or even giving up this activity to take care of the children. Thus, there is an obvious financial impact on these families.[17-32]

The routine of the families, especially of the mothers who play the role of main caregivers, is affected. They have to reorganize things in the face of new responsibilities and constant demands. Thus, these caregivers often have problems in reconciling children care with work outside the home, having to leave their activities outside the home or reduce their journey so as to be able to stay home with their children, offering them all the necessary attention.[12-3]

Most caregivers express difficulties related to living and dealing with children with chronic conditions. Many make comments that this is an unpredictable and sometimes relentless condition, significantly affecting the whole family. The plans and careers are disrupted, and even the ability to find the material means to survive.[18]

According to a study on children with cerebral palsy, the families find it difficult to obtain social support because although the technological advances in the health area saved the life of their child, the society is not prepared to receive them, or to aid in their rehabilitation. Thus, it is not easy to obtain the resources that the children need, and the families have to seek treatment and follow-up through other ways.[36]

The studies also showed that having children with chronic conditions even affects the place of the family's residence; due to the treatment and the need to return to seek professional care, parents choose to live near health facilities, or in the same city where children will be accompanied by health professionals.[17-8]

Stressful experiences affecting the families, and especially mothers, in almost all aspects of their relationships lead them to social isolation. This isolation can lead to profound stress, depression and a subjective decrease in the quality of life of these women and their families.[13]

Regarding health professionals and the diagnosis of children with chronic diseases, a survey found that parents reported conflicts with physicians due to delayed diagnosis and difficult access to specialized services. The research revealed that parents felt that pediatricians had no knowledge of the pathology of their children, or were not sure of how to diagnose them and did not understand the reference and counter-reference process. Parents describe feelings of anger and frustration before the medical staff, with consequent difficulty to access care for their children. They were unaware of the support networks that could help them at the moment, and felt abandoned by health care professionals, mainly physicians.[49]

A study with parents presented their need with respect to information, the need to prepare parents for the care of their children. Parents reported that they found beneficial to receive more information about their children's chronic illness, stressing the importance of education programs to promote more benefits to understanding and caring for children.[18]

It is necessary for health professionals to get involved in the care of children by the use of communication and other instruments to better meet the needs of the families, taking as an example the nursing diagnosis that facilitates, enables and favors a more adequate assistance. In this context, nurses need cognitive skills, experience and scientific knowledge to interpret patient data, and to implement care plans and actions to maintain the quality of the care offered. However, for this to occur effectively, it is essential that nurses create a bond with these families, interweaving care with a social support network in order to provide the necessary assistance for coping with the adversities that arise during the treatment of children with chronic diseases.[21]

After the established diagnosis about the chronicity of the illness of the children, families begin a process of adaptation, seeking to recover their balance. The whole family organization is changed in an attempt to meet the demands of care that the child needs, often breaking the social roles that family members play.[13]

At this context, it is imperative to take care of the families of children with chronic conditions as an initial stage of the treatment process, providing information before discussing treatment options so that they beware of the children needs, monitoring and updating the knowledge and understanding of the family[26]. It is important for health professionals to discuss the needs of the child and the available options for improving care along with families. Together they will be able to realize and transform a dynamic care plan that meets the needs.[16-7]

It is essential that parents receive the same information from different health professionals, so that one professional reinforces the information of the other. This division of labor makes each team member support the other, which is essential for the full care and recognition on the part of all.[23]

Another point that deserves to be highlighted is the process of coping with chronic conditions in childhood is faith in a superior being, as emphasized in many researches.[22,27-8] Prayer by parents and children is the most frequent coping method reported, for the family' believes and religiosity.[22,28] The use of prayer by parents, both individually and in groups, has a very positive meaning.[22,27]

Parents face a reality in which their expectations and plans need to be adjusted due to the condition and limitations that the children present in their situation. They present passive coping (avoiding the problem or reducing the stress that the problem causes)[51] as a coping strategy, represented by the response that confronts people. Behaviors such as praying, resting, and following treatment as directed by a physician as active coping strategies (attempts to directly face the stress-generating event) [51], talking to someone and "go on with life" despite the pain felt are common.[34]

Another way that families find to deal with the diagnosis of their child is to familiarize with and accept the diagnosis. However, these factors are associated with the uniqueness of the people involved, the situation of the disease, and the context in which the disease occurs. There are a number of ways of coping, such as the search for information, the development of skills and adherence to the new lifestyle. However, for this to happen properly, it is important that health professionals perform education activities, clarifying doubts, demystifying myths and offering support, because the onset of an illness always ends up being a shock to values, habits and beliefs of the families.[14]

By understanding the situation in which they are inserted and having a better understanding of the disease, the family members start to face it in a different way, adhering to healthier life habits, so as to promote the child's well-being and minimize undesirable signs and symptoms.[14] In this sense, it is noticed that many changes in family habits take place due to the chronic illness of the child who often needs that the family reorganizes its entire structure, sometimes giving up external activities such as work and socialization with friends. Even food and sleep are also altered due to the care given to the child.

In order to face the new existential situation, in which children and families live, we observed that deep knowledge about the pathology and the connection with faith through prayers are important allies in the process of adaptation. Not only children with chronic conditions need care, but also their whole families, considering that the children will only be cared for if family members have autonomy to provide such care. For this to happen, health professionals need to be attentive to the needs of the families, as well as the school must welcome the children and their families, respecting their needs, and this way forming a great support network.

♦ Care routines of families with the children

Among the routines of care that are required by children with chronic conditions are the needs for love, gregariousness, acceptance, attention and all other psychosocial needs involving affection. This is because humans need care such as this to live, especially children and adolescents. Thus, attention, companionship, attachment, affection, security, freedom, among others, must be satisfied for the maintenance of the family bond.[21]

According to research,[15] parents and family members try to keep the children safe by avoiding quick and unpredictable activities.

Parents describe the tiredness they observe in their children when they experience a very busy day, and they are aware that they put them under many restrictions because they have difficulties seeing their children in pain.

Caregivers point out that many activities that are appropriate for children at their age require some additional assistance from them, such as for taking shower. They understand that children with chronic conditions sometimes need more time to perform certain activities on their own.[35] It is important to note that all human beings have their own time, in which, in their singularity, they develop their potential.[52]

However, self-care is a very important component for efficient disease management[22], requiring parents to discuss these aspects of the disease with the child.

Caregivers commonly report being afraid of the therapy and care needed by the children, even when the treatment is of their choice. They express anxiety and difficulties in understanding routines and daily life.[18]

Families need to help or supervise children when taking medication, dressing, performing hygiene, and eating or having leisure times. The degree of impairment caused by the chronic disease implies a greater or lesser need for care and, depending on the severity of their state, care can become increasingly difficult and endless. And as the children grow, the disability worsens and their needs become more evident. Food is a necessity that has a great impact on the daily routine of the families, even if in some situations the children are able to eat the same diet of the family, many need help for the family member to put the food within reach.[19]

According to a study of children who depend on technology[40], the care routine generates overload and requires intensive care, with respect to medication. The need to take medicines at regular time intervals, day and night, is an important aspect, for it requires care throughout the twenty four hours of the day.

According to a study addressing the Hunter's pathology,[17] the family routine includes trips for which the family needs to organize economic and physical resources. Such trips are one of the main expenses for families residing far from the centers of medical evaluation and follow-up. Another change that occurs in the family routine is the appointments with doctors, which depend on the availability of the professionals and do not give to the families the option of choosing dates and times.[25]

The fear of parents becomes evident when their children need to go to school; they describe the unease at the beginning of school activities and the excessive protection they try to provide, despite recognizing the motivation which is of promoting the independence of their children.[15]

Moreover, it is identified a difficulty to access schools caused by the need to perform some procedures. In some cases, the presence of a caregiver in the educational environment is necessary. Thus, both schools and health services need to be prepared to contribute to the development of these children, respecting their specificities.[53]

Issues of organizational nature, poor structural and human preparedness to receive children and adolescents with special health needs also interfere with access to school.[12] Parents reported that they never received help for the necessary or desired care of their children, and that they often need the physician to inform the school where their children are enrolled about about the educational establishments and programs.[24]

Parents of chronically ill children notice that when their children attend regular schools they meet deficits that portray the neglect of the Brazilian educational system, such as teachers who feel technically and emotionally unprepared to receive these children.[39] There is a need for school-based interventions to help these children to interact not only with their families but with their peers and teachers, so that they may be able to develop skills and values.[33]

The presence of stigma and social exclusion within communities is evident and promotes vulnerability and disadvantages to children with chronic diseases, resulting in poor mental health, social isolation, postponement of education, exclusion from religious organizations and lower health-seeking behaviors.[33] It is at the school environment that children perceive that they are different from others, and when such environment cannot manage these differences, the school can become a space for the perpetuation and maintenance of stigma.[37]

One of the difficulties that mothers face when they take their children to school is in relation to the care for physiological eliminations of their children. Schools do not have anyone to change their diapers and, when such change is necessary, the schools call parents to go there to do it themselves. Professionals in school institutions should receive guidance on how to manage the care with physiological needs of these children.[19]

Interventions with dietary guidelines are needed for children, for their caregivers and for the environment in which they are inserted, and they must be informed in a clear and easily understood language, encouraging the development and practice of self-care in order to make them active in their health process and disease. Thus, knowledge of this process provides a greater sense of control and responsibility for health by encouraging children and their families to take an active stance in the management of their health.[19]

Among the routines in which the families are inserted, the integral and continuous care for the children's comfort, always thinking about the limitations that the children have, are essential. However, these require the intense family (re)planning of activities to better care for the children.

CONCLUSION

Families of children with chronic diseases have their routines altered, often losing control of how to manage their lives with the presence of chronicity. It is noteworthy that the adaptation to the new situation of the child is facilitated when the family is well informed and empowered in relation to the process of living with a chronic condition, being embraced and cared by health and education professionals, thus minimizing the negative feelings that are experienced.

It should be noted that such care occurs in various ways and is facilitated through appropriate tools and strategies, considering and analyzing each individual, so that the specificities may be met. It is important to consider each child and each family as unique to offer adequate support to their needs, aiming at a comprehensive and humanized care.

It is also worth noting that, based on the analysis of the articles published in the last 10 years, it was identified that there is concern about the care of families of children with chronic diseases through interaction, communication and embracement. However, it is noted that there are still barriers for professionals to see families beyond the chronic disease that affects the children.

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