FAMILY CARE WITH CHILDREN AND ADOLESCENTS WITH EPIDERMOLYSIS BULLOSA: AN INTEGRATIVE LITERATURE REVIEW [a]

CUIDADO FAMILIAR À CRIANÇA E AO ADOLESCENTE COM EPIDERMÓLISE BOLHOSA: UMA REVISÃO INTEGRATIVA DA LITERATURA

CUIDADO FAMILIAR PARA NIÑOS Y ADOLESCENTES CON EPIDERMÓLISIS AMPOLLOSA: UNA REVISIÓN INTEGRADORA DE LA LITERATURA

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Objective: to analyze how the family care with children and adolescents with Epidermolysis Bullosa is performed. Method: integrative literature review, held in September 2018 with pre-defined protocol, whose eligibility criteria contemplated eight studies in the final sample, which responded to the following question: How is the family care with children and adolescents with Epidermolysis Bullosa performed? Results: the family care along with their children with Epidermolysis Bullosa is influenced by health professionals' assistance, who are unaware of the illness and, therefore, do not provide the necessary guidance, leaving parents unprepared for the daily care with their children. Conclusion: the scientific literature little addresses the experience of care, within the family, dedicated to their children affected by Epidermolysis Bullosa.

Descriptors: Epidermolysis Bullosa. Child. Adolescent. Caregivers. Family. Nursing.

Objetivo: analisar como é realizado o cuidado familiar de crianças e adolescentes com Epidermólise Bolhosa. Método: revisão integrativa da literatura, realizada em setembro de 2018 com protocolo pré-definido, em que os critérios de elegibilidade contemplaram oito estudos na amostra final, que responderam à seguinte questão: Como é realizado o cuidado familiar de crianças e adolescentes com Epidermólise Bolhosa? Resultados: o cuidado da família junto a seus filhos com Epidermólise Bolhosa é influenciado pela assistência dos profissionais de saúde, que desconhecem

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a doença e, portanto, não proporcionam as orientações necessárias, deixando os pais despreparados para cuidar cotidianamente dos seus entes. Conclusão: a literatura científica pouco se aproxima da experiência desse cuidado, no âmbito da família, dedicado aos seus filhos acometidos pela Epidermólise Bolhosa.

Descritores: Epidermólise Bolhosa. Criança. Adolescente. Cuidadores. Família. Enfermagem.

Objetivo: analizar la forma en que se realiza el cuidado familiar de los niños y adolescentes con Epidermólisis Ampollosa. Método: revisión integradora de la literatura, celebrada en septiembre de 2018 con protocolo pre-definido, en el que los criterios de elegibilidad incluyeron ocho estudios en la muestra final, que responden a la siguiente pregunta: Cómo se realiza el cuidado familiar de los niños y adolescentes con Epidermólisis Ampollosa? Resultados: el cuidado de la familia, junto a sus hijos con la Epidermólisis Ampollosa, es influenciado por la asistencia de los profesionales de la salud, que no conocen la enfermedad y, por lo tanto, no proporcionan la orientación necesaria, dejando los padres no preparados para el cuidado diario de su ente amado. Conclusión: la literatura científica poco aborda la experiencia del cuidado de la familia, dedicado a sus hijos afectados por la Epidermólisis Ampollosa.

Descriptores: Epidermólisis Ampollosa. Niño. Adolescente. Cuidadores. Familia. Enfermería.

Introduction

Epidermolysis Bullosa (EB) is a non-infectious, genetic and rare disease, with chronic evolution, whose main characteristic, due to the mutation of genes responsible for encoding proteins constituents of skin layers, is the fragility of the epithelial tissue, resulting in blisters on the skin and mucous membrane, evolving to wounds(1-2). The manifestations and complications of EB vary according to the type, subtype and age of the individual. In the most serious subtypes, the blisters are generalized, with chronic ulcerations, scar sequelae, involvement of multiple organs, increased morbidity and complications(2).

Epidemiological data in the United States show that the prevalence of the disease is 11.07 cases per one million inhabitants and the incidence is 19.57 cases per one million live births(3). In Brazil, epidemiological data are unknown, because it is a rare disease and is not included in the list of compulsory notification(4). Currently, this survey is being coordinated by the Dystrophic Epidermolysis Bullosa Research Association of Brazil(5), which estimates about 1,600 people diagnosed with EB in the country.

Due to the complexity of the EB, the multiprofessional team must monitor the child and the family who experience this illness(2,6). Among the health professionals, the performance of the nursing staff stand out, responsible for the direct and continuous care with people affected by EB. The authors claim that, as an incurable disease, the EB continuously demands specific care, with an emphasis on preventive measures and skin care, early recognition and treatment of symptoms(2,7-9).

Thus, the nursing staff plays a crucial role both in the treatment of EB as in health promotion and prevention of complications in people diagnosed with this disease. In this sense, an important aspect in the care process of nurses in relation to the EB is the insertion of the family in this context. The family is responsible for caring for a child or adolescent who, at minimum contact, develops blisters that evolve to painful wounds and can lead to death mainly because of secondary infection and anemia(2,8,10-11).

In this context, the complexity of the process of illness of this rare disease(2,6,12) characterizes the continuity of care with children and adolescents with EB, such as a traumatic event, marked by fear, insecurity, concern and suffering of the family caregiver(6-7). This begins to live/experience the unawareness of the rare disease and the uncertainty in relation to the child's survival, considering the risk of death in the first years of life, in serious cases(2,8,11). However, although the family is recognized as the main responsible for the care with children and adolescents with EB, the scientific literature lacks studies addressing the experiences of the care in the family routine(13-15). The available studies of literature review have focused on only the actions and assignments of nursing professionals(7-9).

Thus, the present study is relevant as it presents elements focused on the family care of the family with children and adolescents with EB, which may subsidize behaviors of health professionals, especially nursing professionals, in the promotion and execution of a qualified family-centered care. Thus, this study aims to analyze how the family care with children and adolescents with EB is performed.

Method

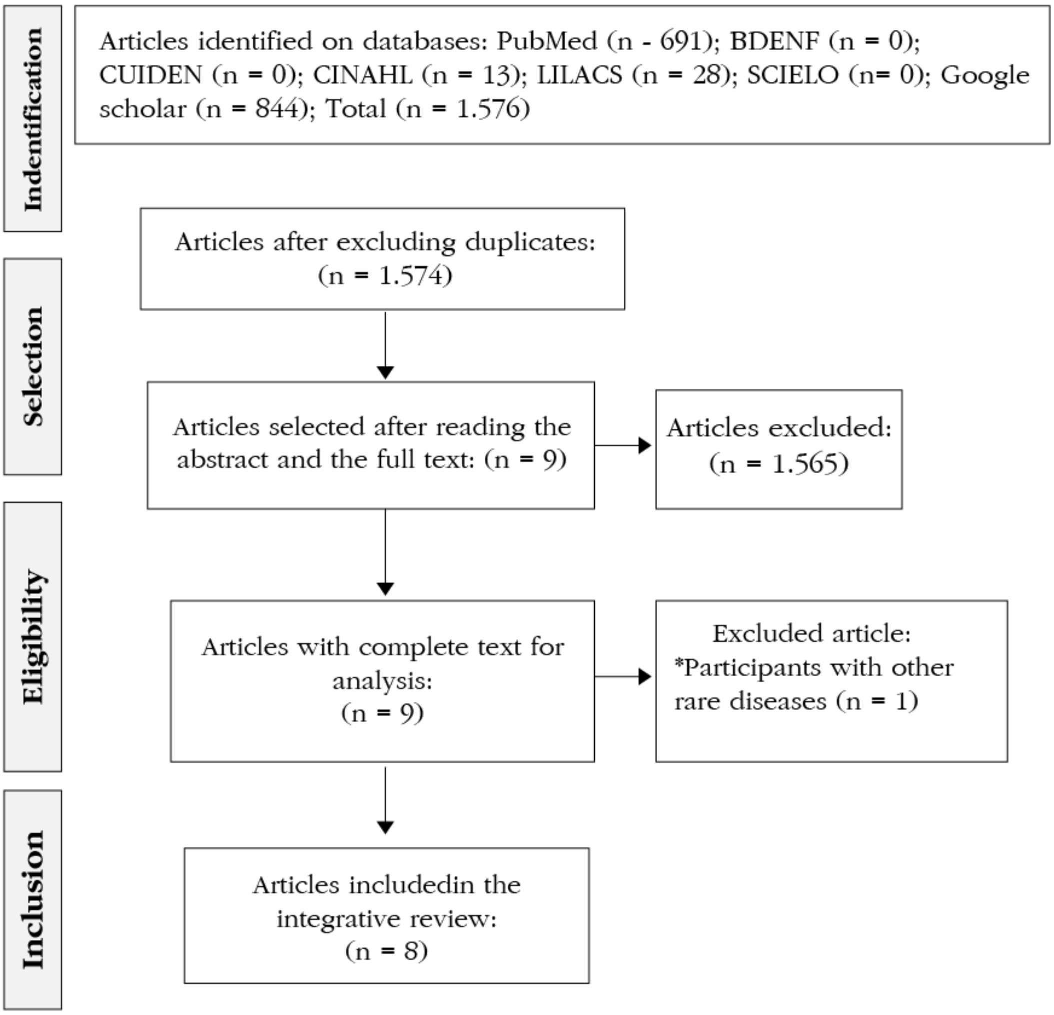
For the study design, the following steps of an integrative literature review were used as pre-defined protocol: choice of the topic and definition of the research question; establishment of inclusion and exclusion criteria; categorization of studies; assessment of studies included in the review; interpretation of the results; and presentation of the review/synthesis of the knowledge present in the analyzed articles(16).

The research question "How is the family care with children and adolescents with Epidermolysis Bullosa performed?" enabled the search for literature to identify original studies that addressed the care, in order to better understand it. The search was performed by two reviewers, independently, in September 2018, on the databases PubMed, Nursing Database (BDENF), *Base de Datos Bibliográfica sobre Cuidados de Salud en Iberoamérica* (CUIDEN), Cumulative Index to Nursing and Allied Health Literature (CINAHL); Latin American and Caribbean Health Sciences Literature (LILACS), Scientific Electronic Library Online (SciELO) and on other sources, such as the Google Scholar.

For the systematic search, the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH) selected were: Epidermolysis Bullosa, Caregivers, Child Care and Adolescent. The term Epidermolysis Bullosa was crossed with the others in Portuguese, English and Spanish, through the Boolean operator AND.

The inclusion criteria established for this review were original articles, complete, fully published, in Portuguese, English and Spanish on the aforementioned databases, regardless of the year of publication. There was exclusion of reflection and review studies, dissertation and thesis, in addition to ministerial documents. Thus, the search returned 1,576 scientific articles, of which, after reading the title and abstract, nine were selected for the complete reading. Then, in the phase of critical reading, only one study was excluded because the participants were families who had experienced the care with children with another type of rare disease. In this way, the corpus of analysis was composed by eight scientific articles, selected according to the PRISMA recommendation, as shown in Flowchart 1.

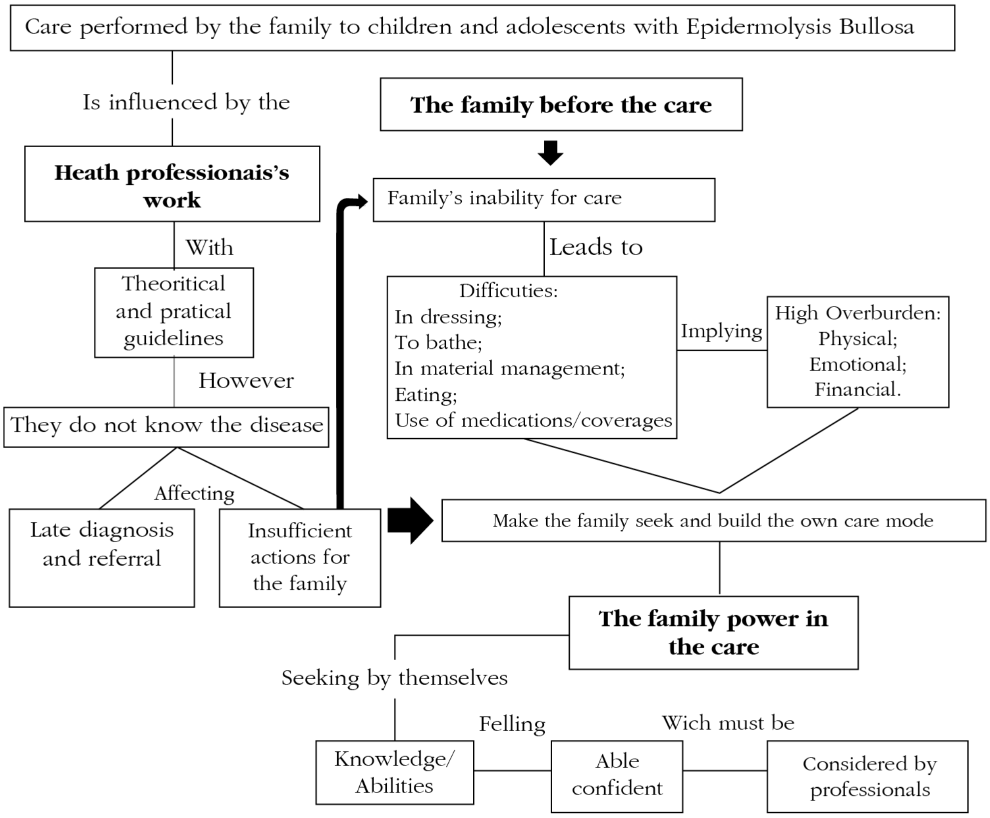
Flowchart 1 – Process of selection of articles



Source: Created by the authors.

In the data categorization, information corresponding to the year of publication, authors, country of origin, objectives, discussions about care, recommendations and conclusions were extracted to a table in the Excel program. After this process, through content analysis, the topics, grouped by similarity, subsidized the construction of the concept map (Figure 1), which presents the main aspects of the literature regarding the care provided by the family to children and adolescents with EB.

Figure 1 – Concept map, with key words, related to the care performed by the family to children and adolescents with Epidermolysis Bullosa



Source: Created by the authors.

Results

The final sample included eight studies. Of these, the majority was held in the Netherlands (38%) by medical professionals (75%), through qualitative approach (50%) and in the English language (88%). Chart 1 shows a summary of the main information extracted from primary studies, based on the objective of interest of this study.

Chart 1 – Studies included in the sample with information on author, year, country, participants, objective, how care is discussed and recommendations/conclusions

(continued)

Number	Author/Year/ Country	Participants	Objective	How care is discussed	Recommendations/ Conclusions
1	Caprara A, Veras MSC[10] 2005 Brazil	3 mothers	To understand from mothers' experience the factors related to psychosocial aspects, mechanisms of adaptation and overcoming.	Based on the responsibility of mothers to assume the role of primary caregiver and description of the care provided in daily life.	The exchange of experience through social networks can provide advances in the quality of life of individuals with EB, social support for family members, awareness of health professionals and managers.

Chart 1 – Studies included in the sample with information on author, year, country, participants, objective, how care is discussed and recommendations/conclusions (continued)

Number	Author/Year/ Country	Participants	Objective	How care is discussed	Recommendations/ Conclusions
2	Singer HM, Levin LE, Garzon MC, Lauren CT, Planet PJ, Kittler NW, et al.(17) 2018 United States	23 children and their caregivers	To identify patterns of antimicrobial resistance in EB wounds and characterize domestic skin care and bathing.	Based on the experience of home bathing and antibiotic use for wounds.	Education regarding the use of antibiotics due to the risk of drug resistance; and appropriate techniques for diluting to the recommended concentrations.
3	Kahraman S, Çiftçi EK, Timuçin A(18) 2017 Turkey	4 families (4 parents and 8 children)	To identify the burden of care of parents who care for their children with EB and the associated factors.	Taking into account the dependence of children for daily care and the high burden for parents.	Parents who receive care support have less burden. Nurses must plan effective strategies, such as training, to reduce this burden.
4	Sampogna F, Tabolli S, Di Pietro C, Castiglia D, Zambruno G, Abeni D(19) 2012 Italy	62 family caregivers	To assess the burden of EB on family caregivers and validate the instrument.	Among the problems most reported by family caregivers, the time spent to provide care stood out.	The Italian version of the validated instrument is useful for measuring the burden on caregivers in cases of skin disease. The study highlights the need for studies on other dermatological conditions.
5	Yuen WY, Duipmans JC, Jonkman MF(20) 2012 Netherlands	16 parents	To identify the needs of parents who have lost their children to EB.	Professional support in referral and home care is one of the parents' needs.	The health professional must also meet the individual needs of the parents.
6	Tabolli S, Pagliarello C, Uras C, Di Pietro C, Zambruno G, Castiglia D, et al.(21) 2010 Italy	42 families	To assess the burden faced by the family with children aged 0 to 7 years with EB.	Based on the high burden faced by the family in relation to aspects of care.	The burden of EB on the family depends on the severity of the disease and the extent of blisters and wounds on the child's body. It is necessary to offer supportive interventions, such as more information about the disease, training and fostering social relationships.

Chart 1 – Studies included in the sample with information on author, year, country, participants, objective, how care is discussed and recommendations/conclusions (conclusion)

Number	Author/Year/ Country	Participants	Objective	How care is discussed	Recommendations/ Conclusions
7	van Scheppingen C, Lettinga AT, Duipmans JC, Maathuis KGB, Jonkman MF(22) 2008 Netherlands	11 families	To understand the problems faced by parents of children with EB according to severity.	Most of the problems faced by parents are linked to the care needs required by their children.	The problems faced by parents are very similar, seeming to differ in intensity according to the severity of the disease. Intervention programs for parents should focus on supporting coping processes, strengthening family relationships and providing moments of leisure.
8	van Scheppingen C, Lettinga AT, Duipmans JC, Maathuis CGB, Jonkman MF(23) 2008 Netherlands	9 families with 11 children	To understand the problems faced by children with EB.	In carrying out daily care, such as bathing and dressing, pain is one of the main aspects to be faced by children.	The main problems faced by children are itching, pain, visibility of the disease and social acceptance.

Source: Created by the authors.

Discussion

The analysis of primary studies enabled the emergence of three categories that present the main trends of publications about the care provided by the family to children and adolescents with EB. The first, "The health professional in the care with the family that experiences the EB", presents the influence of the assistance provided by health professionals in the care performed by family. The results showed that doctors and nurses were often unaware of the disease, which resulted in late diagnosis and inadequate guidelines on the care needs of children with EB. The second category, "The family before the care required in the EB", discusses the difficulties to perform the care required in the daily routine of children and adolescents with EB. In this sense, the family builds the knowledge necessary to care for their children, based on their own experience of care. The third and final category, "The family's experience and power in caring for the EB", presents the continuous movement of the family to acquire knowledge and develop skills for care, generating the feeling of confidence, which must be considered by health professionals.

The health professional in the care with the family that experiences the Epidermolysis Bullosa

The analyzed studies showed the importance of health professionals throughout the process of care of families with children and adolescents with EB. Thus, recommendations for the care in the EB shall begin at the child's diagnosis, still in the maternity or as soon as possible, performed by a multidisciplinary care in a specialized center, ensuring the follow-up since pediatric age to adulthood, to provide guidelines and behaviors focused on the person and the family, individually, respecting each situation(2). Nevertheless, the studies expose the lack of medical professionals and emphasize, in particular, the lack of knowledge to diagnose the disease, which results in incorrect and late referrals(20-22) and interferes in the adequate prognosis and treatment(2,6). In relation to the nurse's work, a study identified improper behavior during the hospital care, with prescription of inappropriate treatments for the treatment of wounds(22).

Addressing this aspect, a study(18) with four families in Turkey found that, despite having received information from health professionals about the EB and how the care should be developed, mainly in the treatment of lesions, the guidelines were completely theoretical, generic and superficial. The limited and punctual attention of health professionals regarding the EB, with insufficient clarification, late diagnosis and referral, jeopardizes the care exercised by the family of children and adolescents(22). The follow-up by a health professional should be regular in cases of EB, to assess the skin and mucous conditions, the general health status, besides the problems exposed by the individual and the family. The regularity of follow-up must take into account the type of EB, the clinical complications, the specific complaints and the conformity of the person and the family with the condition of illness(2).

In this context, the nursing's role as a care profession stands out. One must reflect on the nurse's place in the multiprofessional team and how he/she is working and/or subsidizing family care with children and adolescents with EB. The authors emphasize that nursing professionals play a preponderant role in the EB, since they participate actively in the care with patients in hospital and outpatient care(2,7-9). Their tasks involve procedures for control and relief of pain, assessment of signs of infection, general skin care and dressings, in addition to supporting those patients and their relatives(2,7-9). The nursing's role in primary health care stands out, which, moreover, performs the continuity of care for patients at home(7). In this way, in the multiprofessional health team, nursing professionals correspond to the category that is, with greater frequency, in direct contact with the families of children and adolescents with EB, through continuous care in all health levels.

Thus, the nursing staff represents the professional category that spends most of the time with children and adolescents diagnosed with EB and their families. Thus, such professionals need to be able to provide a comprehensive care, through training and update courses. Furthermore, the production and dissemination of knowledge through studies addressing the theme in the nursing area also stand out.

The family before the care required in the Epidermolysis Bullosa

In the case of illness of a relative by EB, the family assumes the responsibility to provide the required care. Studies have pointed out the mother as the main caregiver in EB. In Italy, for example, two studies identified that 82% and 84.7%, respectively, of the caregivers of children with EB were mothers(19,21). In the Netherlands(22) and in Brazil(10), the participating families decided that child care would be the mother's responsibility, while the father would work to ensure the family income.

Given this scenario, the mothers needed to cope with the changes in the family routine and reconcile the chores and daily care of the ill child, dedicating, in severe cases, almost exclusively to the care with their children with EB(10). The care load given to the family relates to the severity of the disease and body surface area affected by cutaneous and/or mucous lesions(18, 21). In severe cases, the family has greater physical and emotional overburden, primarily by the demand for care with pain, in the practice of dressings, time of dedication and costs with the treatment, which can favor the development of psychological problems, such as depression and anxiety(19,21-23).

The permanent need for attention for the person with EB is mainly related to skin care(2), the main organ affected by the disease. Most included in this review discuss, briefly, the family care concerning the EB, without emphasis on the valuable experience of the family, in relation to acting and coping with difficulties in the development of such care, mainly associated with the attempt to prevent skin trauma(10,17,22-23). Therefore, they defend what was called "minimal handling" of the child, in addition to the attention with clothes and the use of lubricants, in an attempt to prevent the fusion of the fingers, as well as promoting elongation of the hands, bathing and dressings(10,17,22-23).

In this context, one of the understandable concerns of the family is the fear of harming the child's skin with the development of new blisters and wounds(10). Initially, the recommended strategy is being careful when handling newborns and infants, since the disease, combined with the immaturity of the skin and functional adaptation to the extra-uterine environment, can lead to the development of cutaneous and mucous lesions and, thus, to potentially fatal infections(2,6). Other relevant recommendations to maintain the skin integrity is the attention with disposable diapers, tight clothing, with high seams and labels in contact with the skin, as well as hard shoes, with internal seams that can cause blisters(2).

A study(10) pointed out that the families adhered to those requirements and began to pay attention to the clothes used by their children. In some cases, the children were kept naked, because, in this way, the contact was smoother and the lesions, scarcer. Other suggestions are decisive for the direct protection of the skin in places considered vulnerable to trauma, such as knees and elbows, like the use of layers of soft silicone and gloves, when the child begins to crawl, walk or practice sports(2,6,12). Other recommendations include using padding in the shoes, the protection of the rim of glasses in contact with the nose and ears, frequently sanitizing toys, which must be manufactured in soft material, as well as choosing the practice of sports with low risk of skin trauma (swimming, singing, music, computer) and using the air conditioning in hot climates(2,6,12).

Authors also observed that the fusion of the fingers due to the healing process is one of the complications in severe cases of EB that leads to the encapsulation of hands and feet(2). Fingers should be separated through dressings with silicone foam cut into strips or gauze soaked with paraffin. Nonetheless, over time, the spaces are gradually lost and the fusion develops(2,12). There are no records that, in an attempt to avoid this fusion, parents try to stretch the fingers daily(22).

The acute and chronic pain is a constant in the lives of individuals with EB, regardless of the subtype, and underlies the daily procedures, such as bathing and dressings, constituting the most debilitating symptom of this disease(2,6,20,23). In EB, whatever the subtype of the disease, pain denotes a characteristic of neuropathic pain, and affects quality of life and socio-economic activities of the affected(24-25). The care proposal, in these cases, is choosing pharmacological and non-pharmacological treatment, which varies according to the age, psychological state, type and severity of pain and the procedure to be performed(2,12). Also for pain relief, the salt diluted in water in specific concentration during the bathing is indicated(12). This practice has been accepted in many cases by families, who use the salt with bleach or pure mixed in water for bathing their children(17).

To assist in the cleaning of wounds, there is the prescribed use of antiseptics diluted in bath water, such as sodium hypochlorite or vinegar, to prevent bacterial growth in wounds and decrease the risk of infection(2,12,17). The use of diluted bleach is recommended in specific concentrations in the scientific literature, so that its action is effective and does not irritate the skin or impede the healing of wounds(11-12). However, a study conducted in the United States found that, although the families receive printed instructions on the proper use of bleach and the indicated concentrations, in the daily bathing of their children, the dilution was performed at concentrations well below the recommended(17).

The execution of daily dressings is a challenge to be faced by the family. For parents, the daily exchange of dressings causes emotional implications, because, while caring for blisters and wounds, they have the sensation of being causing pain to children(21-22). In an attempt to reduce pain during this procedure, before the removal of the dressings, the suggestion is to immerse each wound in warm water or saline solution for approximately 5 through 10 minutes, or even performing the technique within the bath, when possible(6,12).

Regarding the use of coverings for wounds, a recent study conducted in the United States identified that parents are unaware of the indication of topical antibiotics used in the treatment for EB(17). The contamination and colonization by bacteria is very common in the wounds of the EB. The use of antibiotics in such cases should be careful, because the recommendation is for infected wounds with colonization of bacteria, paying attention to the frequent change of medicine, reducing the resistance or sensitivity(2,6,11). In practice, however, the families do not comply with recommendations and always use the same antibiotics on healthy skin and clean wounds(17).

These results encourage discussions about the family's inability in the care required in the illness of their children. The studies demonstrate the family's inability in caring for the EB, notably in the early years of a child's life, when attention must be redoubled, in consequence of the emergence of skin blisters when carried on the lap, breastfed and caressed(10). These events lead to empirical care practices, based on the knowledge that the experience itself imposes, without taking into account the professional guidelines and recommendations, such as the use of bleach for the bathing and topical antibiotics for wounds(17).

Thus, the support of health professionals is essential, especially nurses, in the family care required by EB. Due to the high burden imposed by the disease on the family, nurses must act seeking effective strategies to minimize the burden and support the family care(18), as well as disseminate theoretical guidelines grounded in scientific guidelines, as well as provide practical training with the family on the proper techniques for the care of this disease(17,21).

The family's experience and power in caring for the Epidermolysis Bullosa

Although the family faces various difficulties, in addition to the inability to put into practice the care required in the EB, mainly in the first years of life, in particular by not knowing the progression of the disease and the way of dealing with the appearance of blisters and wounds at every moment, as times goes by, this family will acquire important experiences to keep the childcare(10). Thus, in consequence of the chronic evolution and of the intense and daily care demands in EB, especially in severe cases, the family ends up assimilating skills to maintain the care and enhance their knowledge about the peculiarities of illness experienced by the child.

Families, mobilized by the empathy awakened by the care, refer to themselves as experts in the care with the EB and claim the prospect of maintaining supervision and strict control over the professional behaviors and being actively involved in all phases of the care with their children(20,22). This ability in family care is recognized by the current international guideline responsible for guiding the best care practices in EB. The propositions emphasize that the person and the family members are experts in the management of their condition, and their involvement is essential in the care process(12).

In relation to professionals' behaviors, in some cases, the family needs to stand not to allow invasive therapies that will only prolong the suffering of their child(20). However, when the experience and knowledge of the family are taken into account by health professionals in decisions relating to the treatment, the family contributes to the well-being of their child. In severe cases, for example, the option to begin using wheelchairs to facilitate locomotion, the decision about the surgery for the correction of the fingers, in cases of fusion, and the procedure of gastrostomy, due to problems in swallowing and eating can be measures shared with the family of children and adolescents with EB(22).

The attitude and the participation of parents in therapeutic procedures have been described in other cases of illness by rare diseases, such as the Schinzel-Giedion Syndrome, a disease that involves numerous losses to the life and health of the newborn(15). In this study, the parents were active in the suggested professional behaviors and sought to evaluate each indication, considering the benefits. Sometimes, they gave up on procedures that could provoke more suffering, such as surgery for hypospadias presented by the child, which would be more esthetic than necessary.

In addition to the experience acquired by families households providing knowledge to contribute to professional behaviors, authors mention the intention of mothers to exchange experiences with other mothers who live the same situation, in order to articulate local associations and exchange of knowledge that can be added in the care performed(10). Thus, the nurse must prioritize care coupled with a family experience in this context, as well as promote spaces for discussion in which the mothers and other family caregivers can express their anxieties, fears and share their unique experiences as support, coping and mutual support strategy.

As a limitation of the study, the articles analyzed little approach the experience of family care performed in everyday life. In this sense, they contribute with reflections about the need for health professionals, especially nursing professionals, support families in the care with children and adolescents with EB in daily care. The present study stands out by its novelty in relation to the care exercised by the families of children and adolescents with a rare disease, such as the EB, and by its contribution to the body of scientific knowledge on the theme.

Conclusion

The present study analyzed how the family care with children and adolescents with EB occurs, through an integrative literature review. It was possible to discuss the proposed objective in the light of the trends of publications on the theme, which allowed constructing the knowledge in three conceptual aspects. The first category, called “The health professional in the care with the family that experiences the EB”, discussed the influence of the assistance provided by health professionals in the care performed by family. In this way, studies pointed out that doctors and nurses are often unaware of the disease, resulting in delayed diagnosis and inadequate guidelines on the care needs of children with EB.

The second conceptual element is configured in the category “The family before the care required in the EB”, which presents the difficulties of families in performing the care required in the daily routine of children and adolescents with EB, underlining that the family builds the knowledge necessary for the care of their child based on their own everyday experience. Thus, the third conceptual aspect identified in the present study, “The family’s experience and power in caring for the EB”, highlights the continuous search of the family for knowledge and skill development for caring with self-confidence.

It is imperative to foster discussions on rare diseases in the academic and health services, as well as instigate the construction of knowledge through new studies that bring scientific evidence and different experiences of care in EB. Given the lack of such studies, new researches should be carried out, aiming to approach care practices already performed within the family, moving beyond the bathing and dressings, which would allow nursing professionals to work closely to the everyday life of families and guide therapeutic procedures based on scientific knowledge.

Collaborations:

1 – conception, design, analysis and interpretation of data: Ronaldo Antonio da Silva, Solange Pires Salomé de Souza and Fabiane Blanco Silva Bernardino;

2 – writing of the article and relevant critical review of the intellectual content: Ronaldo Antonio da Silva, Solange Pires Salomé de Souza, Fabiane Blanco Silva Bernardino and Lidiane Cristina da Silva Alencastro;

3 – final approval of the version to be published: Ronaldo Antonio da Silva, Solange Pires Salomé de Souza, Fabiane Blanco Silva Bernardino and Lidiane Cristina da Silva Alencastro.

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