Revista de Enfermagem do Centro-
Oeste Mineiro
2020;10:e4133
DOI: 10.19175/recom.v10i0.4133
www.ufsj.edu.br/recom

Original Article

A VIVÊNCIA DO CUIDADO MATERNO A UMA LACTENTE COM EPIDERMÓLISE BOLHOSA

EXPERIENCE OF MATERNAL CARE TO AN INFANT WITH EPIDERMOLYSIS BULLOSA

EXPERIENCIA DEL CUIDADO MATERNO DE UN LACTANTE CON EPIDERMÓLISIS BULLY

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RESUMO

Objetivo: Compreender o cuidado materno realizado a uma lactente com Epidermólise Bolhosa. **Método:** Estudo de caso único com abordagem qualitativa realizado com a mãe de uma lactente com seis meses de idade e diagnóstico clínico de Epidermólise Bolhosa. A recolha dos dados ocorreu em dois encontros em domicílio da participante por meio de entrevista em profundidade e observação. Empregou-se a análise de conteúdo do tipo temática. **Resultados:** A partir das vivências do cuidado materno empreendido a lactente, emergiram duas categorias temáticas: dificuldades enfrentadas no cuidado materno à lactente com Epidermólise Bolhosa e aspectos que fortalecem o cuidado materno à lactente com Epidermólise Bolhosa. **Considerações finais:** Os profissionais de saúde precisam proporcionar suporte e esclarecimentos à mãe e à família diante das dificuldades que porventura surgirem, bem como incentivar, valorizar e explorar os aspectos que fortalecem o cuidado materno nesse contexto de adoecimento crônico e raro.

Descritores: Doenças Raras; Epidermólise Bolhosa; Lactente; Cuidadores; Enfermagem.

ABSTRACT

Objective: To understand the maternal care provided to an infant with Epidermolysis Bullosa. **Methodology:** This is a single case study with a qualitative approach carried out with the mother of a six-month-old infant diagnosed with Epidermolysis bullosa. Data collection took place in two meetings at the participant's home through an in-depth interview and observation. Thematic and content analysis was used. **Results:** From the experiences of maternal care given to the infant, two thematic categories emerged: difficulties faced in maternal care for infants with Epidermolysis Bullosa and aspects that strengthen maternal care for infants with Epidermolysis Bullosa. **Final considerations:** Health professionals need to provide support and clarification to the mother and family in view of the difficulties that may arise, as well as encourage, value and stimulate the aspects that strengthen maternal care in this context of a chronic and rare disease.

Descriptors: Rare Diseases; Epidermolysis Bullosa; Infant; Caregivers; Nursing.

RESUMEN

Objetivo: Comprender el cuidado materno que se brinda a un lactante con Epidermólisis Bullosa. **Metodología:** Estudio de un caso único con abordaje cualitativo realizado con la madre de un niño de seis meses y diagnóstico clínico de Epidermólisis Bullosa. La recolección de datos se llevó a cabo en dos reuniones en el domicilio del participante a través de una entrevista en profundidad y observación. Se utilizó análisis de contenido temático. **Resultados:** De las experiencias de la atención materna realizadas al lactante surgieron dos categorías temáticas: las dificultades enfrentadas en la atención materna del lactante con Epidermólisis Bullosa y los aspectos que fortalecen la atención materna del lactante con Epidermólisis Bullosa. **Consideraciones finales:** Los profesionales de la salud deben brindar apoyo y aclaraciones a la madre y a la familia ante las dificultades que puedan haber surgido, así como incentivar, valorar y fortalecer los aspectos que fortalecen la atención materna en este contexto de enfermedades crónicas y raras.

Descriptores: Enfermedades Raras; Epidermólisis Ampollosa; Lactante; Cuidadores; Enfermería.

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How to cite this article:
Silva RA, Santos RES, Alencastro LCS, et al. Experience of maternal care to an infant with epidermolysis bullosa. Revista de Enfermagem do Centro-Oeste Mineiro. 2020;10:e4133. [Access_____]; Available in:______. DOI: http://doi.org/10.19175/recom.v10i0.4133

INTRODUCTION

Rare diseases are usually triggered by genetic mutations that lead to pathophysiological changes in the body and their prevalence is low(1). Currently, six to eight thousand rare diseases are known, that is 6% to 10% of all the diseases(1). Among rare diseases, it is possible to highlight Epidermolysis Bullosa (EB), a hereditary, non-contagious, systemic genodermatosis, with great clinical variation whose main characteristic is epithelial fragility(2-4).

Clinical evolution of EB depends on the type and subtype and severe forms can reach several organs with a high probability of death in the first years of life(2,4). Complications vary according to the severity of the disease and include alterations in almost all systems of the body, with greater predisposition to the development of dermatological neoplasms, growth delay, malnutrition and chronic inflammation(2,4-5).

Epidemiological data of EB may vary according to the country and be difficult to accurate, due to the lack of a specific information system to evaluate its distribution(6). In Brazil, there are no epidemiological records since the disease is not on the list of compulsory notification and diseases of the Ministry of Health, which contributes to the lack of information on its distribution. On the other hand, in the United States, the prevalence is 11.07 cases per one million inhabitants, with an incidence of 19.57 cases per one million live births(6).

Due to the complexity and chronicity of EB, the family continuous care after hospital discharge is crucial. In this context, the mother stands out as the main caregiver of children diagnosed with EB, assuming this complex and continuous role in the family routine(7-10). Moreover, the results of a recent review on family care for children and adolescents with EB showed that the mother, in particular, constructs the necessary knowledge and skills from her own daily experience, considering the particularities imposed by their child's condition(9).

In this framework, the question is: how does the mother experience care of her infant daughter diagnosed with EB? This study is relevant since it approaches the experience of motherhood, both of difficult aspects and favorable aspects present at birth and in the care given to a child diagnosed with EB. Such knowledge can help nursing professionals to center care on the family. Thus, given the complexity of being a mother of a child with a rare disease and specific care demands, especially in the first year, this study aims to understand maternal care given to an infant with EB.

METHOD

Considering the representativeness of the case investigated being EB a rare disease, we chose a single case study method with a qualitative approach. Thus, the theoretical and methodological framework of this study are case study assumptions, taking into account concepts that characterize a phenomenon investigation in its real context(11).

The case focused on this investigation was identified through social media, and the selection process established the following inclusion criteria: being 18 years old or older; being the mother of a child under one year old with clinical or genetic diagnosis of EB, since it is the most critical period for care; being a user of *Sistema Único de Saúde* (SUS); and living in the researcher state of action to enable data collection.

The techniques use to empirical data collection were in-depth interview (IDI) and observation. IDI consists on a conversation with intentionality, a flexible interview strategy that does not need scripts and that seeks memories in a non-linear way, respecting the dynamicity of the subject's narrative(12). Thus, the core question ‘How is your experience of giving care to your daughter with EB?’ allowed to gradually deep the memories and narratives of the participant of the study(12).

The fieldwork was based on meetings at the participant's home with previously scheduled dates and times, based on her preference and the least interference in daily life, respecting her privacy. Therefore, two meetings were scheduled between February and March 2020. Soon after each of them, to complement and enrich the IDI, the researchers registered the observation records with the individual perception of the thoughts, the researchers’ intuitions, as well as the manifestations of the participant, such as looks, gestures, postures, silences, in addition to the description of objects and scenarios(12).

To organize the data, all empirical material collected was typed in the Research Journal(13), which contains the transcriptions of the IDI with full narratives and observation records. The corpus of analysis of this study consisted of a file, typed in Word, with 56 pages. Thematic content analysis, followed by analysis organization, codification, categorization and inference(14), led to two thematic categories: difficulties faced in maternal care of the infant with EB and aspects that strengthened maternal care of the infant with EB.

This study was evaluated and approved by the Research Ethics Committee of the *Universidade do Estado de Mato Grosso* (CEP/UNEMAT) under *CAAE*: 26311819.2.0000.5166 and opinion number 3,779,764. The ethical commitment was mediated the participant and the coordinating researcher signature of the Free and Informed Consent, respecting the ethical precepts of research with human beings established in resolution no. 466/2012 of the National Health Council of Brazil.

RESULTS

This case study observation and analysis center was the mother of a six-month-old female infant with clinical diagnosis of EB. The participant is a 26-year-old woman, brown-skinned, Protestant, university student, married and living with the biological father of her only daughter, in a city in the interior of Mato Grosso-MT, Brazil. According to the mother's narratives, the infant was born by C-section, with cutaneous aplasia in the right lower limb, in a hospital in the interior of the state and was transferred to the reference hospital in the capital city, after seven days.

After her daughter's, birth and diagnosis, the mother reported that the support given, especially from her parents and husband, was crucial for the infant care. After hospital discharge, the mother recalls that she was only able to take effective care of the baby at home after a month. Based on the experiences of this mother, the analysis of the empirical material led to two thematic categories, which contributed to the discussion about the aspects that hindered and those that strengthened the acquisition of knowledge and skills necessary for maternal care of the infant with EB.

Difficulties faced in maternal care of the infant with Epidermolysis Bullosa

The first difficulties, reported by the mother in the care of her daughter with EB, began shortly after delivery. The lack of knowledge of health professionals at the infant's birth hospital about the rare disease as the first barrier to be faced. The mother stresses that the suspicion of the clinical diagnosis of EB was inferred between two or three days after delivery, when a doctor discussed the case with other professionals from the reference hospital in the capital city of the state, as expressed in the narrative: “The doctors also did not know what was happening. No one knew, they just thought she had some kind of infection, but it was negative! This doctor searched with other doctors at the [capital hospital] and they came to [a possible conclusion] that she could have Epidermolysis Bullosa (Mother)”.

According to the participant of the study, even though the clinical diagnosis, the nursing team was unaware of the specificities necessary for giving care to a child with EB. The mother recalls that “The nurses who were at the time taking care of us, they also did not understand the severity of the disease [...] they wanted to treat her like any other patient, but unfortunately she was not another patient, she had EB (Mother)”.

After the hospitalization period, the difficulties mentioned by the participant regarding home care were directly related to the particularities of contact/touch with the skin of the infant with EB: “The wounds appeared as if it were magic. She was fine, we looked at her skin that was smooth, five minutes later she already had a blister or a wound [...] The way we took her was giving her the traumas, so we thought it was a very, very serious infection that was peeling her skin (Mother)”.

This specificity also led the mother to have difficulties in breastfeeding, which was interrupted on the third day after birth, due to the rapid clinical evolution of the disease: “We started trying breastfeeding. It looked like she was hungry! Then every time we tried she cried, cried and didn't want to. But when she didn't nurse, she cried too. [...] I began to realize that she was in pain, she wanted to, but she was in pain. Then I realized she had a mouth wound. [...]. The insistence caused an injury in her mouth, and created the blood bubble (Mother)”.

Also, about maternal care, the complexity dressing was also mentioned as an aspect that hindered maternal care and, consequently, the construction of skills to deal with the disease. The mother recalls the moment she was discharged from the hospital and could not make the dressings in her daughter's foot, a place that had extensive cutaneous aplasia since she was born. The procedure was time consuming, caused a lot of pain in the infant, which caused anguish and suffering for the mother: “[The infant] was discharged and then it was a real war to learn to take care of her. Learn how to make the dressings. And at that moment I couldn't do the bandages.

The first month I wouldn't go into the room. When they were going to bandage her foot, I went out. She cried a lot. I tried not to listen, because it was a desperation not to be able to do anything, not to be able to take the pain away. Because nothing helped at that moment (Mother).” “[...] She cried a lot and, it's like this, about three to four hours to make the bandages. She had a lot of pain, sometimes she pooped because of the pain (Mother)”.

In addition, the mother's narratives point to her need to be heard by health professionals. The participant mentions a lack of reception, the feeling that health professionals were not listening to her needs, concerns and apprehensions, another aspect that hindered taking care of her daughter with EB. In the experience presented in this study, there was a lack of listening and dialogue in the interaction between the mother and health professionals: “You have to listen to what the mother says there, at that moment. Because there are a lot of people, nurses and doctors who don't listen. They think their studies [are] what matters. Sometimes we complain about something, it is not nonsense. There are a lot of professionals who think we're teaching, but it is not. We want what's best for our daughter. I tell you [health professionals] to just listen more to the patient! (Mother)”.

Despite the acquisition of knowledge and skills for maternal care in EB, it was possible to identify hindering aspects, which need to be considered and minimized by health professionals who provide care to the mother and family. According to the narratives above, it is essential that these professionals assist in the maternal care of children with EB, giving adequate support from listening to the needs of mothers and family members and what they say about the specificities of EB. Thus, according to the participant of the study, there were also some knowledge and conducts that strengthened maternal care of the infant.

Aspects that strengthened maternal care of the infant with Epidermolysis Bullosa

According to the participant of the study, some factors of her experience giving care to an infant with EB, also contributed to strengthening care. In this regard, the family support received, especially by her mother, was very important since her daughter’s birth and had a boosting effect on care.

The mother says that, in the first month of the infant's life, she was not able to perform the dressings on her daughter and, in this period of the disease, the family assumed the responsibility of doing them daily. Thus, the family support received, soon after the birth of the infant, favored the construction of technical skills to take care and, over time, the mother was able to assume her role in her daughter’s care: “Thank God I had my mother and stepfather. They were a lot stronger than me. Because [in] the first month I didn't go into the room, I couldn't see her bruises, I couldn't see her. She cried about one to two hours without stopping at the time of the dressings (Mother)”. “[The dressing] of the little hand we already did, but of the foot, I started doing it after a month. It was already a little healed. It wasn't a little injury, it was a deep thing, we had to wash it and it bled frequently (Mother)”.

In addition to family support in these moments of difficulties, another element that proved to be a booster of maternal care of the infants with EB came from the knowledge the mother acquired on the Internet. In her experience, the participant mentioned she searched for information available online about EB immediately after the clinical diagnosis of her daughter. According to the mother's narratives, this way of seeking knowledge began during hospitalization: “When the doctor said it was that disease, I, as a mother, went after information. I researched. I was inside the hospital, since I didn't sleep, I kept searching and searching. I've read a lot about Epidermolysis Bullosa. I didn't want to believe it was, because when you go to internet, what you see it's horrible (Mother)”.

From the mother's narratives, it was possible to verify that search for information about EB and experiences of daily care promoted the construction of knowledge and skills required to give care to her daughter. She also talked with knowledge and mastery about the specificities of the disease experienced in her maternal care, as presented in the following observation note: “She explained everything, made a point of talking about the prices of each one and the benefits of all creams, from those used to moisturize, the simplest dressings to the most expensive ones. She explained everything she knew about the disease. I confess that I was surprised by all that knowledge (Notes of observation; February 15, 2020)”.

Assuming empowerment over her daughter's condition, the mother began to become a reference for other mothers and families facing the same situation of EB. Because of this learning, she began to be contacted through social networks and asked to exchange experiences about the daily care she gave to her daughter, to offer support to the families of other children affected by this disease: "Many mothers contact me: how do you do this or that? Like yesterday, one o'clock in the morning, I was talking to a mother about which cream was the best, because her daughter was full of wounds (Mother)".

DISCUSSION

The results of this study indicated the difficulties and aspects that permeated maternal care with an infant with EB. Thus, it was possible to understand that the first difficulty reported by the mother was felt soon after the birth of her daughter, that is, the lack of knowledge of the health professionals about EB. Researchers point out that the birth of a child with a rare disease, such as EB, imposes great challenges on health professionals because it is an uncommon, little known disease with a variety of clinical pictures depending on the different subtypes(8,15).

The lack of preparation of health professionals to perform the clinical diagnosis and adequate management of EB injuries was also evidenced in other studies, which report that since the child's birth, parents have experienced feelings of anxiety, insecurity, stress and loneliness, due to the lack of knowledge of the professionals about the disease(7,9-10). Thus, it is necessary to emphasize the need for health professionals to be based on a specific and updated literature, according to the guidelines that guide the best therapeutic approaches to the family, especially the mother, improving knowledge and skills for continuing care at home(8-9). Thus, we highlight, as priorities, permanent educational actions from health services and spreading information relevant to awareness about EB among professionals in the area(7,9).

Another difficulty exposed corresponds to the difficulty in performing the dressing, specificity of EB care. Authors illustrate the complexity of EB disease, as a result of the extreme dermatological fragility resulting from the clinical evolution of the disease(8-9). Depending on the particular characteristics of EB, any trauma can lead to the development of new blisters that evolve to wounds, which require specific care, especially in the contact/touch with the skin(8).

In addition, another important finding mentioned by the participant of the study as an obstacle in the maternal care of her daughter with EB, concerns breastfeeding, which was impaired by skin injuries that are typical of the disease. In situations like that, authors point out that it may be possible to introduce breastfeeding in infants with EB in specific cases, provided that the mother is properly guided and accompanied by health professionals trained in EB care, a process that should be continuously evaluated and reconsidered in case of blisters and wounds(2-3). The case of a newborn with three days of birth and clinical diagnosis of EB confirms the results of this research, who refused oral feeding due to injuries in the gums, palate and labial mucosa(8).

Another peculiarity of EB care is dressing, essential and daily procedure in the treatment of the injuries. This procedure is considered as the most suffering experience due to pain, even with analgesics and, to the time demanded for dressings, especially in severe cases(7). Thus, due to its complexity, parents find it difficult to perform it. Some authors note that parents feel they cause more pain and suffering to their child during dressing, instead of attenuating pain(9). In view of this, it is essential the support of health professionals during hospitalization, assisting and offering subsidies for the acquisition of knowledge and skills aimed at ensuring longitudinal care(8).

Moreover, it is important to recognize listening and dialogue as important attributes to build bonds in the assistance of people and families who experience some chronic condition and rare disease. In this study, the mother's narratives exposed, among other difficulties, health professionals lack of listening to her longings, needs and apprehensions, being an obstacle in taking care of her daughter with EB. With regard specifically to EB, the guidelines imperatively reinforce the need to consider and involve the family in the direct care of the child(2). However, a study conducted in the state of Mato Grosso, which included the experience of parents taking care of their child with Schinzel-Giedion Syndrome, a rare disease, also identified, in the participants' statements, the lack of bond and dialogue with health professionals, urging the family to seek help in other services or sectors to be able to offer the best care to the child(16).

In addition to the aspects that created obstacles to maternal care to infants with EB, the mother also mentioned aspects that contributed to strengthen this process, such as family support, which the mother mentioned as a positive factor that helped to give care to her daughter with EB. Some authors(15) show that, although the mother assumes the role of main caregiver, the family support received at home is fundamental to endure different situations of rare conditions and diseases. In addition, a study emphasizes that the social support network should be built throughout the life of the person who experiences a rare disease, as it is also important to face the adversities imposed by the disease, and health professionals need to validate this constructive process(10).

The participant of this study also described information search about the disease on the Internet as a factor that helped in the acquisition of knowledge about taking care of infants with EB. The search for clarifications about diseases, such as EB, is described in other studies as something inherent to health professionals lack of information about the rare condition experienced by the family(15). In this context, when faced with a disease that health professionals little or completely unknown, the mother, recognized as the main caregiver, needs to look for information and build subsidies to take care of the child(7,9).

Thus, as in the present study, looking for clarification in other sources, such as the Internet, as well as the experiences of daily care, provides the mother with skills and mastery to face the particularities of the disease(9). In the case under study, the experience of the disease also led to the construction of a net of support for other mothers of infants with EB, through social networks. Authors also point out that the empowerment of those involved in the care of a person with a rare disease can provide the exchange of experiences with other families in the same situation, by projecting the other’s reality, influencing a safe environment, crucial to maternal care to the child(1).

FINAL CONSIDERATIONS

The study allowed us to understand the aspects that hindered and strengthened the maternal care of an infant diagnosed with EB. Thus, one of the complicating aspects of this process was the health professionals lack of knowledge about EB, the particularities of the disease, the complexity of dressing and the health professionals lack of listening in the interaction with the needs, and apprehensions of the mother caregiver in her experience with the disease. The aspects that strengthened the experience of maternal care were family support, the search and availability of information about the disease on the Internet, which, together with daily experiences, boosted the acquisition of knowledge and skills by the mother to support maternal care at home, as well as the exchange of experiences with other families, through social networks.

Considering the difficulties and aspects that strengthened maternal care through the experience of the mother of an infant with EB, it is crucial to ensure that health professionals, especially nurses responsible for nursing care, act based on comprehensive care, providing support to the mother in the face of difficulties, as well as to encourage and explore aspects that have strengthened care in the context of a chronic and rare disease.

This study is relevant because it shows the priorities of mothers of infants with EB, which can help health professionals, especially nurses, to build comprehensive care both in tertiary care, during hospitalization, and in primary care, through the continuity of home care. Thus, it is emphasized the need to promote studies that investigate other rare diseases, to contribute and subsidize health policies and services that address the needs of people and families who experience this type of illness.

As a limitation of this study we highlight, that the findings presented correspond to the experience of only one mother giving care to her daughter with Epidermolysis Bullosa. Due to the rarity of the disease and the absence of an information system that tracks families of children with rare diseases, identifying these potential participants is still a challenge in Brazil. In this regard, future studies may perform an active search for cases with more in-depth analysis through the experience of other mothers with children diagnosed with EB.

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Note: Study originated from a Course Completion Work presented to the Faculdade de Ciências da Saúde of the Universidade do Estado de Mato Grosso for the acquisition of a bachelor's degree in Nursing.

Received in: 04/10/2020
Approved in: 17/12/2020

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