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RESEARCH | PESQUISA

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Experiences of mothers in the care of children and adolescents with epidermolysis bullosa

Vivências de mães no cuidado a crianças e adolescentes com Epidermólise Bolhosa

Experiencias de madres en el cuidado de niños y adolescentes con Epidermólisis Ampollosa

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ABSTRACT

Objective: to know and analyze mothers' experiences in caring for children and adolescents with Epidermolysis Bullosa. **Method:** a descriptive qualitative study was developed with ten mothers of children and adolescents with epidermolysis bullosa from different regions of Brazil using semi-structured interviews recorded remotely using Google Meet® between September and November 2021. The thematic analysis technique guided the appreciation of the empirical material. **Results:** mothers aged between 23 and 53 years participated in the study. Two categories translate the maternal experience: i) the "shock" of the diagnosis and the initial challenges and ii) "Stop living to live for them": the changes in the families' daily life. **Final considerations and implications for practice:** mothers experienced fear and insecurity when their child was diagnosed, and the care routine, especially the daily dressing changes, caused a physical and emotional burden. These results can support the follow-up of these families to provide them with care tools and emotional support.

Keywords: Adolescent; Child; Nursing; Epidermolysis Bullosa; Mothers.

RESUMO

Objetivo: conhecer e analisar as vivências de mães no cuidado a crianças e adolescentes com Epidermólise Bolhosa. **Método:** estudo descritivo de abordagem qualitativa desenvolvido junto a dez mães de crianças e adolescentes com Epidermólise Bolhosa de diferentes regiões do Brasil, a partir de entrevistas semiestruturadas, áudio e vídeo gravadas, por via remota, utilizando-se a plataforma Google Meet®, entre setembro e novembro de 2021. A técnica da análise temática direcionou a apreciação do material empírico. **Resultados:** participaram do estudo mães com idade entre 23 e 53 anos. Duas categorias traduzem a vivência materna: i) O *"baque"* do diagnóstico e os desafios iniciais e ii) *"Deixar de viver para viver para ele*": as mudanças no cotidiano das famílias. **Considerações finais e implicações para a prática:** as mães vivenciaram sentimentos de medo e insegurança diante do diagnóstico do filho e a rotina de cuidados, em especial, as trocas diárias de curativos, acarretaram sobrecarga física e emocional. Esses resultados podem subsidiar o acompanhamento dessas famílias de modo a instrumentalizá-las para o cuidado e apoiá-las emocionalmente.

Palavras-chave: Adolescente; Criança; Enfermagem; Epidermólise Bolhosa; Mães.

RESUMEN

Objetivo: conocer y analizar la vida de las madres en el cuidado de niños y adolescentes con Epidermólisis Bullosa. **Método**: estudio descriptivo de abordaje cualitativo desarrollado junto a diez madres de niños y adolescentes con Epidermólisis Bullosa de diferentes regiones de Brasil, a partir de entrevistas semiestructuradas con grabación de audio y video, por vía remota, utilizando la plataforma Google Meet®, entre septiembre y noviembre de 2021. La técnica de análisis temático dirigió la apreciación del material empírico. **Resultados**: participaron en el estudio mujeres de entre 23 y 53 años. Dos categorías traducen la experiencia materna: i) El "*shock*" del diagnóstico y los retos iniciales; y ii) "*Dejar de vivir para vivir por él*": los cambios en la vida cotidiana de las familias. **Consideraciones finales e implicaciones para la práctica**: las madres experimentaron sentimientos de miedo e inseguridad ante el diagnóstico de su hijo y la rutina de cuidados, especialmente los cambios de apósito diarios provocaron una sobrecarga física y emocional. Estos resultados pueden servir de apoyo para el seguimiento de estas familias, con el fin de poder cuidarlas y apoyarlas emocionalmente.

Palabras clave: Adolescente; Niño; Enfermería; Epidermólisis Bullosa; Madres.

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INTRODUCTION

Epidermolysis bullosa (EB) belongs to a group of phenotypically different genodermatoses that can be hereditary or acquired. It is generally characterized by skin fragility with blistering or other lesions and can affect mucous membranes.[1] There are over 30 subtypes of EB categorized into four groups: i) epidermolysis bullosa simplex, ii) junctional epidermolysis bullosa, iii) dystrophic epidermolysis bullosa, and iv) Kindler epidermolysis bullosa.[2]

There are an estimated 500,000 people with EB worldwide, mostly children and adolescents. The incidence in the United States of America (USA) is 19.57 cases per one million live births.[3] In Brazil, there is no robust epidemiological data because EB is not on the list of diseases and conditions of compulsory notification.[4]

Regarding the challenges this population faces, the difficulty in defining the diagnosis and early and timely initiation of treatment stand out, in addition to weaknesses in access to supplies, impairing the continuity of care.[4,5] Pain is a common experience among people with EB, especially when facing the need to perform daily dressings.[5,6] Dressing changes usually represent a traumatic experience for the child/adolescent and parents and caregivers, although they should not be neglected due to the risk of infection;[1] the false idea that it is an infectious disease also harms social relationships.[4] In general, the condition negatively impacts the quality of life of the affected person and the family.[7]

A recently published scoping review with the study question "What are the support needs of parent caregivers of children with EB?" identified 11 studies that met the inclusion criteria, mostly from Europe and North America.[8] No Brazilian studies were included in this review, indicating a lack of national studies on the topic.

Given the above, this study was based on the following questions: How is the experience of mothers in caring for children and adolescents with EB? What are the challenges and coping strategies adopted? Hence, this study sought to understand and analyze mothers' experiences in caring for children and adolescents with EB.

METHOD

This is a descriptive study with a qualitative approach, which seeks to recognize and analyze different perspectives by valuing subjective characteristics and individuality.[9] As for the study participants, the inclusion criteria were: being the mother of a child or adolescent with EB and being over 18 years old. The exclusion criterion was not being the main person responsible for the child's care. Despite this exclusion criterion, it was not necessary to apply it; all the mothers who expressed interest in participating were the primary caregivers of the child or adolescent.

In order to locate and recruit potential participants, electronic searches on social networks (Instagram® and Facebook®) were conducted using the term 'epidermolysis bullosa.' Several groups and pages of non-governmental organizations (NGOs) that support families of children and adolescents with EB and/or disseminate information and awareness about the disease were found.

We then searched the list of members of these groups or pages, paying particular attention to the users who interacted with the posts. The search was done for open social network profiles that often contained in their descriptions the reference to the child with EB, as well as the disclosure of publicly available pictures of the child/adolescent. The invitation was sent individually by direct message on the registered social network profiles of the participants.

The message contained a personal introduction, the study's objectives, and the first author's e-mail address so those interested could contact her. The invitation was sent by private message to 48 participants, of which 14 mothers initially expressed interest; however, four were not present virtually on the scheduled day and time. The researcher contacted them to reschedule and did not obtain an answer. Thus, a convenience sample of ten participants was formed. Notably, the study was requested to be disclosed on the social networks of NGOs and pages related to the theme, albeit no interest was shown.

After expressing interest in participating in the study, the informed consent form was provided for reading. After the agreement, the remote interview was scheduled via the Google Meet® platform. This platform was chosen for its familiarity and ease of use, as well as for being free of charge. Moreover, it is a resource that ensures data security and privacy as the data is encrypted.

Empirical material production occurred between September and November 2021, and the interviews were conducted by the first author (a Nursing undergraduate student) through previous training provided by the supervisor and co-supervisor with qualitative research experience. Hence, the initial questions sought to characterize the mothers in terms of age, marital status, education, occupation, and income, as well as characterize the child or adolescent with EB in terms of sex, age, age at diagnosis, and the number of hospitalizations in the last year. The second part of the interview was developed according to the following guiding questions: "tell me about your experience in taking care of a child with EB," "tell me about the repercussions and challenges of having a child with EB," and "tell me about the strategies you use to face these challenges." All interviews were audio recorded and lasted roughly 30 min.

Notably, the interviews were conducted remotely due to the COVID-19 pandemic. Among the advantages of this strategy, the possibility of interviewing mothers from several Brazilian regions stood out; a limiting factor was the impossibility of the researcher being present and observing the life context of these women, which would undoubtedly enrich the empirical material.

Next, the audio and video interviews were transcribed in full and underwent the analytical processes recommended by the thematic content analysis method,[10] starting with skimming the text of the transcripts. After successive and thorough readings to explore the empirical material produced, the data were coded according to their similarities and differences and grouped into thematic categories. Chart 1 presents a summary of how the analytical process took place until the construction of the thematic categories, which were: i) The "shock" of the diagnosis and the initial challenges and ii) "Stop living to live for them": the changes in the families' daily lives.

All ethical precepts for studies involving human beings were followed. The project was reviewed and approved by the Research Ethics Committee (CAAE no. 48589221.0.0000.5393 and opinion no. 4.952.903 from September 2021). Data confidentiality was ensured by identifying the participants by the letter "P" followed by an ordinal number according to the order in which they were interviews.

RESULTS

Ten mothers (nine biological and one affective) participated in the study, aged between 23 and 53 years; six reported living with a partner, three were divorced, and one was single. As for their levels of education, most had completed high school, three had completed higher education, and one had incomplete elementary school education. The family's per capita income ranged from 275 to 6,250 BRL, an average of 1,321.83 BRL. Most of them (60%) did not have a paid job. The remote application allowed the participation of mothers who lived in different regions of Brazil — six from the Southeast, three from the Northeast, and one from the South.

The children and adolescents with EB were aged between 2 and 16 years old, five were female and five were male. In most cases (90%), EB diagnosis was confirmed within the first three days of life (90%). Only one child required hospitalization in the last year (three times).

The *"shock"* of the diagnosis and initial challenges

According to the mothers, the diagnosis of EB was unexpected and led to numerous feelings. The feeling of mourning before the rupture of the idealized and healthy child occurred abruptly and intensely at birth:

> *In the beginning, it's the scare, you know? There is the mourning that you have to do for the idealized child because it is a disease that does not appear in the prenatal check up, [in the] pregnancy.* P9
>
> *As a first-time mother, I expected the child to be healthy because I did everything correctly during the pregnancy. And then, when the child is born like this, it's a shock, you know?* P7
>
> *My feet left the ground; I don't think I even felt the ground beneath my feet. It felt like the world came crashing down on me*. P3

Still, the unexpected diagnosis caused outrage and questions about God's justice, as well as negative feelings:

> *Of course, no one expects to have a child with any kind of problem; I had a moment of outrage, of questioning myself (...) I thought the worst things in relation to her and myself, questioning God, like, why did this happen to me? I did everything right.* P1

Given it is a rare disease, most mothers were unaware of it, with the intensification of fear and uncertainty. In this sense, the beginning of the trajectory was marked by many challenges, especially due to the unprecedented nature of the experience:

> *It's not easy. In the beginning, it's very difficult, everything is new. We had never heard of epidermolysis bullosa, it's all new.* P6
>
> *It was very difficult initially because I had never heard about it. In the first days, it was very difficult, you know?* P7
>
> *It was quite frightening, you know. I had never seen that in my life.* P2

Chart 1. Coding of research data. Ribeirão Preto - SP, Brazil, 2021.

Initial codes	Intermediate codes	Thematic categories
✓ Expecting a healthy child	Grief with the rupture of the idealized child	The "shock" of the diagnosis and initial challenges
✓ Despair at the diagnosis		
✓ Outrage		
✓ First contact with the disease	Lack of knowledge and insecurity when caring for a child with EB	
✓ Impactful images of the injuries		
✓ Challenges of caring for injuries		
✓ Extreme tiredness	Physical and emotional repercussions and the importance of the support network	"Stop living to live for them": the changes in the families' daily lives
✓ Difficulty in resting		
✓ Neglected self-care		
✓ Help from family or professionals		

Faced with the surprise, the initial search for information on the Internet was present, although the impacting images of the injuries had a negative repercussion:

> *The worst thing a mother does is search the Internet because it is devastating, the Internet is the worst thing (...) the Internet makes it fifty thousand times worse; it has images, very grim stuff. So, initially, it was brutal, it was terrible. I was floored; I had no reaction.* P10

Nonetheless, the impact is lessened when there is a history of personal experiences with children with EB or cases in the family, providing an exchange of experiences in care and constituting a support network in coping with the disease:

> *I had my aunt who has a daughter with EB, so she passed on to me the care she already had with her...So in my case, although it was difficult, it was even a little easier than some mothers who have no notion whatsoever of the disease.* P8
>
> *We already had a daughter with this disease, the first daughter, you know? That was the surprise of everything... just the day-to-day to show that we are capable of.* P10

After the initial impact of the diagnosis, which in most situations occurs in the maternity ward, comes the time of hospital discharge and consequent transition of the newborn with EB to the home under the care of the family (usually the mothers). The daily care, such as bathing, changing clothes, and dressings, represented a challenge given the complexity of the child's condition associated with the lack of knowledge to perform these procedures. Participant number one (P1) used the expression "*everything is very intense*" to refer to this moment, a perspective also portrayed by mothers four and five:

> *From bathing, dressing, and breast-feeing, it was all very intense at that moment, all very intense.* P1
>
> *The first days we go crazy, that's the truth.* P5
>
> *It was very difficult because I hadn't even held a bandage; I didn't know anything about these procedures. To puncture blisters, dressings, nothing, we didn't know anything.* P4

However, as time passes, mothers accumulate experience and feel less distressed about daily care. Thus, the experience acquired by P1 enabled relaxed and playful management of her daughter's daily dressings in order to minimize the child's physical and emotional suffering:

> *Nowadays, I have gotten used to it; she is already 11 years old. I got used to dealing with EB." I don't let her feel under the weather; I try to be always very funny, I play with her when applying the dressings, even with the dressings, I draw a picture on the dressing, you know, I cut heart-shaped dressings*. P1

The initial reactions with the intention of protection lead the mothers to isolate the child, putting them "inside a bubble." The stress related to the disease caused the behavior of excessive care with the child and home environment, especially cleaning, to protect against infections. In this perspective, P10 describes her fear of receiving visits soon after hospital discharge and how, after some time, she became calmer and sought balance in order to maintain a normal life:

> *When you get home, you are already neurotic; you don't want anyone in your house because you are afraid of people passing something on to her. You clean the room twenty-four hours a day with alcohol, and it is that really crazy neurosis (...) then you learn with the day-to-day that your daughter can be normal, that your daughter is protected with the covers, that she won't catch anything, that you don't need to protect her from the world.* P10

*"*Stop living to live for them": the changes in the families' daily lives

Although somewhat more prepared to manage EB, the demand for constant attention and care, household chores, and formal work leads to fatigue, sleep deprivation, and overload, causing physical and emotional repercussions for mothers.

> *I just work, work (...) it seems like it doesn't, but everything increases, practically every day you change their bedding, it is a house that must be a little bit cleaner because of contamination and everything.* P5
>
> *The battle is considerable; the fatigue is extreme because there is the whole work routine, then when we get home, there is the issue of [the child] not sleeping well, that is, if they don't sleep well, we can't rest either; it's very tiring, very tiring indeed.* P6

Faced with doing the best for their child, they often neglect their own needs and self-care. Women get used to and adapt to this type of behavior, maintaining it for long periods, drastically changing their lives to live primarily for the care of their children, as exemplified by the following exerpts:

> *The last time I went to the doctor was when I had my youngest child (laughs).* P3
>
> *There is no time left, and you end up forgetting about yourself and getting used to being like that.* P5
>
> *We end up getting a little sloppy. I used to be able to go to the gym and do my nails and hair, but today I can't do it. Dad used to go on walks, but we can't do that either. Today we do what we can, and when we can, our priority*

> *our child. So, we changed our lives a lot to fit him in our lives; we stopped living for ourselves to live for him.* P6
>
> *I guess I got a little careless. Because I only think about her; I only care about her. Her being well is what matters, you know?* P7

In contrast, some mothers recognize self-care as essential for their physical and mental well-being and make efforts, in an attempt to adapt their routines, to reconcile and incorporate actions in this direction:

> *I recently started to look after myself, I started to see a psychologist because I was reaching a limit. I forgot myself completely.* P4
>
> *I take care of myself at home, do my hair at home, and do my nails at home, all by myself.* P10

Favorable economic conditions and a structured and strengthened social support network proved to be determinants to enabling moments of leisure and self-care. However, this reality is not the most frequent for most of the mothers interviewed:

> *I have a housekeeper and I have a nanny. So, it is a different reality than most mothers. I do Pilates, I swim with my son, and if I feel like going out for coffee in the afternoon, I go out and have my coffee. I have time for myself and can go out because I know that my daughter will be well taken care of.* P9
>
> *I have a lot of help from the father, in spite of us being separated, he stays with her every 15 days on the weekend; I have my mother who helps me. In these moments, I take advantage to do my nails and my hair, to take care of myself, and to do therapy.* P1

DISCUSSION

This study presented mothers' experience in caring for children and adolescents with EB, revealing their initial emotions when faced with the diagnosis while still in the maternity ward and their tensions with daily care.

According to our findings, most (six) of the mothers stated that they live with their partners. Nonetheless, in an epidemiological survey in the USA, a high incidence of divorce was identified in families with children with EB, especially in the most severe cases of the disease.[3] The care and attention to the needs of the child with EB is an event that causes physical and mental stress and can potentially impact the marital relationship.[11] Moreover, the greater severity of the child's condition negatively impacts the couple's sexual relations and the decision not to have other children.[5,12]

Another impacting factor on the family dynamics is the spouse's difficulty understanding the disease's complexity and the care required.[12] Mothers are the main ones responsible for the child's care and, consequently, the most affected in this process,[12,13] making it fundamental for health professionals to encourage paternal involvement in the care of the child with EB.[13]

The average monthly income of the mothers participating in this study was 1,321.83 BRL, and most had no paid activity. An investigation in eight European countries addressed the socioeconomic burden resulting from EB. According to the authors, the costs are due to care directly or indirectly related to health, such as transportation, acquisition of medication, specialized medical consultations, exams, and supplies for dressing and, finally, the loss of productivity of the main caregiver.[14] Indeed, a North American study concluded that the disease causes financial burdens even for those who have health coverage since not all expenses are reimbursed, such as dressings and wound materials.[15]

Another result found is regarding the challenges experienced by the participating mothers after the birth and confirmation of their child's diagnosis of EB, primarily due to the lack of knowledge about the disease and insecurity about providing care at home. Parents experience a wide range of emotions at the birth of a newborn with EB, which lasts throughout the child's life.[12] There is shock, anxiety, denial, loss of hope, fear, and overwhelm at birth. They may even reject or avoid seeing the baby, possibly due to the impact of the newborn's condition and the appearance of skin lesions.[12,15,16]

A qualitative study conducted in Ireland also portrayed the fear of the unknown and the need for emotional support;[5] according to the authors' findings, dressing changes were a particularly difficult task, as they caused intense pain to the child, and this suffering was unbearable for the parents, yet the support of the nursing professional was positively evidenced.[5]

Other investigations corroborate this by pointing out that the daily care of injuries invokes feelings of sadness, anxiety, anger, despair, stress, and helplessness in caregivers, and feelings of guilt may emerge because they feel responsible for the child's pain during care and dressing changes.[6,11,16,17] In fact, the levels of anxiety and negative feelings experienced by parents are directly related to the intensity of the child's discomfort and anxiety; therefore, involving the child in care and implementing playful approaches to distract them may be effective strategies to cope with these negative feelings during the care with injuries.[18]

Maternal overload was also identified in this study, with emphasis on the overlapping of the care for the child with EB with household chores and/or formal work. According to an integrative literature review that analyzed the family care of children and adolescents with EB, the need to reconcile domestic chores with the daily care of the ill child is recurrent. However, this reality negatively impacts these women's quality of life and socio-professional activities.[4] The physical and emotional repercussions are evidenced, especially with exhaustion, sleep deprivation, and frustration when reconciling work and child care, with symptoms such as loss of appetite and weight and headaches.[15,17,18]

According to a qualitative study conducted in Taiwan, the demand for continuous care impairs the quality of sleep and increases anxiety and depression, reinforcing the emotional and physical fatigue of these family members.[15] Furthermore, one study analyzed a case of a newborn with EB in a children's hospital in southern Brazil and identified tension in the role of the caregiver as a possible nursing diagnosis, reinforcing the need for interventions that address this aspect.[1]

In this study, one of the mothers had a more favorable socioeconomic status which allowed her to count on a professional to take care of her child. According to her report, such support allowed more flexibility in her routine, including leisure and caring for her healthy child. In this sense, the recommendation of psychological support, especially for family caregivers with lower socioeconomic status, presented by a quantitative study that aimed to analyze the quality of life of 80 caregivers of children with EB in Iran, is in line with the results presented herein.[7]

Some mothers experienced the opportunity to count on the support of family members in order to minimize the burden, corroborating the reports of some Irish parents who also received informal support from friends and relatives.[5] Nevertheless, the authors emphasized that it is common for parents to be afraid of leaving their children with EB with other people, mainly for fear of getting hurt.[5] However, it is essential to promote moments of leisure, recreation, a vacation period, and the maintenance of social life to strengthen the family unit.[17]

Despite the negative impact of the Internet being described in this study due to the initial impact of the images of skin lesions caused by EB, social networks have been gaining notoriety for enabling the sharing of experiences among families in the same situation in order to enlighten them about the specifics of child/adolescent care.[16,19]

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Our findings lead us to conclude that this study met the proposed objective and answered the research questions. In general, mothers experienced fear and insecurity when facing the birth of a child with EB, although these feelings decreased as they acquired knowledge and skills to handle the situation. The care routine, especially the daily dressing changes, caused a physical and emotional overload.

As regards the implications for practice, this study can support follow-up actions for children and adolescents with EB and their families since it provides a synthesis of the challenges experienced as well as potential support strategies. Furthermore, we recommend the nursing team strengthen its role in health education, providing assertive and timely tools to these mothers regarding the care required, and thus support them emotionally.

The limitations of this study are the small number of participating mothers and the impossibility of conducting face-to-face interviews. Given this context, it is relevant to develop new research to expand the number of participating mothers and include other family members such as fathers, grandparents, uncles, and siblings.

AUTHOR'S CONTRIBUTIONS

Study design. Carolina Balestra Silva. Nayara Gonçalves Barbosa. Aline Cristiane Cavicchioli Okido.

Data collection. Carolina Balestra Silva. Nayara Gonçalves Barbosa.

Dat analysis. Carolina Balestra Silva. Nayara Gonçalves Barbosa. Aline Cristiane Cavicchioli Okido. Diene Monique Carlos. Monika Wernet.

Interpretation of the results. Carolina Balestra Silva. Nayara Gonçalves Barbosa. Aline Cristiane Cavicchioli Okido. Diene Monique Carlos. Monika Wernet.

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Responsibility for all aspects of the content and the integrity of the published manuscript. Carolina Balestra Silva. Nayara Gonçalves Barbosa. Aline Cristiane Cavicchioli Okido. Diene Monique Carlos. Monika Wernet.

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