

# ORIGINAL ARTICLE

## Parental Caregiving Experiences in Epidermolysis Bullosa: A Phenomenological Study

Hassan Khalili<sup>1</sup>, PhD candidate; Hossein Karimi Moonaghi<sup>2</sup>, PhD; Hamid Reza Kianifar<sup>3</sup>, MD; Zahra Sadat Manzari<sup>2</sup>, PhD

<sup>1</sup>Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran;

<sup>2</sup>Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran;

<sup>3</sup>Department of Pediatrics, School of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran

### Corresponding Author:

Zahra Sadat Manzari, PhD; Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Postal Code: 91379-13199, Mashhad, Iran

Tel: +98 51 38846730; Fax: +98 51 38846734; Email: manzariz@mums.ac.ir

Received: 10 June 2024   Revised: 17 December 2024   Accepted: 24 December 2024

### ABSTRACT

**Background:** Epidermolysis bullosa (EB) is a rare, inherited disease characterized by mucocutaneous fragility. It requires continuous family support and caregiving. However, insights into the complex realities of daily caregiving roles for parents remain limited. This study aimed to explore the lived experiences of Iranian family caregivers caring for their children with EB.

**Methods:** This phenomenological study was carried out from February to November 2023 at Mashhad Akbar Hospital or participants' homes. Purposeful maximum variation sampling was used to recruit 10 parents (3 fathers, 7 mothers) who met the inclusion criteria. Data were gathered through in-person, semi-structured interviews and analyzed using Van Manen method in MAXQDA software version 2020.

**Results:** Caregivers' experiences elucidate the profound adversity endured by parents raising children with EB. Four themes emerged from the data: "lost and confused about care and treatment"; "trapped in endless cycle of hardship caring"; "inevitable self-isolation"; and "bitter and deteriorating family life".

**Conclusion:** Family caregivers who provide care for children with EB face numerous difficulties, leading to significant stress and heavy responsibilities. Their lived experiences provide a comprehensive picture of the physical, psychological, and social difficulties related to this rare disease.

**Keywords:** Caregivers, Child, Epidermolysis bullosa, Parents, Qualitative research

**Please cite this article as:** Khalili H, Karimi Moonaghi H, Kianifar HR, Manzari ZS. Parental Caregiving Experiences in Epidermolysis Bullosa: A Phenomenological Study. *IJCBNM*. 2025;13(2):149-160. doi: 10.30476/ijcbnm.2025.102011.2466.

## INTRODUCTION

Epidermolysis bullosa (EB), also known as butterfly disease, is a rare genetic skin disorder that causes recurring blistering of the skin and mucous membranes throughout a person's lifetime. The skin blisters very easily from even minor mechanical friction or trauma.<sup>1</sup> Managing EB requires extensive ongoing care and support from family members.<sup>2</sup> Major difficulties faced by EB patients include swallowing issues due to blistering and scarring in the throat, making it challenging to consume solid foods or liquids.<sup>1,3,4</sup> Additional complications are numerous, including bowel/digestion troubles, intestinal enlargement, premature tooth decay, watery eyes from tear duct obstruction, widespread severe blistering and associated disfigurements, mobility impairment, anemia, malnutrition stemming from eating difficulties, and chronic infections.<sup>1,5</sup>

Patients with EB are usually hospitalized during initial diagnosis and acute flare-ups, with most care administered at home by family members requiring constant support.<sup>6</sup> Raising a child with this illness can be physically and emotionally demanding for caregivers as they endure years of this without any relief or positive changes in disease recovery. However, the condition tends to worsen over time in most cases.<sup>7</sup>

Literature reveals that EB caregivers must monitor patients' needs extensively, creating substantial physical and emotional strain.<sup>7-9</sup> Compared to other chronic diseases, EB demands more comprehensive family support, profoundly impacting the family system.<sup>10</sup> Given these exceptionally challenging caregiving circumstances, caregivers of patients with EB are often referred to as "secondary patients" or "hidden patients," who themselves require and deserve services, support, and guidance.<sup>11</sup> Furthermore, several qualitative studies have reported that these caregivers face numerous psychosocial challenges, including stress, anxiety, depression, and social isolation.<sup>9, 12</sup> Additionally, they often struggle to

maintain a balance between their caregiving responsibilities and other aspects of life.<sup>12</sup>

However, studies conducted in Iran have predominantly been cross-sectional, focusing mainly on the quality of life and caregiving burden of these caregivers.<sup>13, 14</sup> While providing valuable information, these studies cannot offer a comprehensive understanding of caregivers' lived experiences. They cannot fully reflect the cultural, social, and religious complexities of Iranian society that may influence the caregiving experience. Iranian culture, with its emphasis on family values, religious beliefs, and unique social structures, can significantly shape the parents' experiences of caring for children with EB.<sup>15</sup> Concepts deeply rooted in Islamic Iranian culture, such as trust in God, patience, and finding meaning in hardships, may substantially impact the parents' coping strategies.<sup>16</sup> Moreover, differences in the healthcare system, access to support resources, and specific social attitudes in Iran can impact the challenges, coping strategies, and particular needs of Iranian parents.<sup>17, 18</sup> Examining this issue within the Iranian cultural context may reveal new and valuable findings. Therefore, conducting a qualitative phenomenological study could contribute to a deeper and more comprehensive understanding of these parents' experiences.

Given the aforementioned problems, there was a recognized need for data derived from the profound issues faced by these families, and researchers deemed it necessary to pay greater attention to the caregivers of these patients and their lived experiences in caring for their children. Therefore, considering the limited qualitative studies conducted in this field and the absence of a similar study in Iran, this research was undertaken with the aim of exploring live experiences of the parents of children with EB.

## MATERIALS AND METHODS

This qualitative study employed Van Manen's interpretative phenomenology and was

conducted from February to November 2023. The study population consisted of parents of children with EB who were referred to Mashhad Akbar Hospital. They attended the hospital for periodic examinations of their child(ren). We had prepared a comprehensive list of all patients visiting Akbar Hospital in collaboration with the hospital's Center for Rare Diseases. Patients and their parents typically visited the hospital on specific days according to a schedule arranged by the hospital. Our research team was present at the hospital on these designated visit days.

Using purposive sampling, we selected parents who met the inclusion criteria for interviews. Inclusion criteria were parents who had been caring for their child with EB for at least 2 years, had full ability to communicate, and were willing to share their experiences. Exclusion criteria were unwillingness to continue participation at any stage of the study, parents whose child had deceased, and detection of substantial inconsistencies in the provided information. Interview locations and times were mutually determined by researchers and participants. According to the participants, the interviews were conducted either at the hospital or their homes. Four interviews were conducted at the participants' homes, and six interviews were conducted at the hospital. Home interviews were scheduled when the participants were not engaged in caring for their child(ren) to ensure that the interviews could be conducted without distractions and in a peaceful environment. Hospital interviews were also conducted in a quiet room, and according to the participants' preferences, after their patient visits, so that the parents could participate in the interviews without any concerns.

A purposeful maximum diversity sampling method was employed, considering children's ages and caregiving duration. We intentionally included a parent with two affected children. The final sample represented both fathers and mothers caring for children with EB, reflecting diverse participant characteristics.

In-depth, semi-structured interviews were used to collect information. To gain a

deeper and more authentic understanding of caregivers' lived experiences, we used the openness or reduction technique within van Manen's phenomenological framework.<sup>19</sup> Initially, researchers made a purposeful effort to identify their presuppositions and prior knowledge about caring for children with EB. They then temporarily set these preconceptions aside to approach the caregivers' experiences with an open mind. The researchers listened attentively and non-judgmentally to caregivers' narratives, allowing their experiences to be fully expressed. Throughout the research process, they continuously reflected on how their perspectives might influence data interpretation, ensuring a more genuine representation of the caregivers' experiences. To enhance parental participation, the researcher established a trusting relationship with participants both before and during the interviews. This was achieved by attending hospital patient visit days and participating in the parents' education process. On the day of the interview, the researcher carefully explained the objectives and significance of the study to parents using simple, accessible language. The interviews, ranging from 27 to 65 minutes in duration, were audio recorded and subsequently transcribed verbatim either on the same day or at the earliest possible opportunity. Data saturation was achieved after ten in-depth interviews, where new data yielded redundant information without revealing novel concepts or themes.

Participants were asked probing questions such as "What is the experience of caring for a child with EB like?" and "How does having and caring for a child with EB impact your life, family, and health?". Exploratory questions for clarification were asked based on participants' responses, e.g. "Can you explain that further?". The questions were designed based on Van Manen's recommendations to focus on describing the participants' lived experiences rather than seeking their perceptions, viewpoints, opinions, or interpretations. All participants

were assigned a code based on the order of their interview for preserving confidentiality. Data were analyzed using Van Manen's 6-step method<sup>20</sup> in MAXQDA software version 2020. The six steps of van Manen's approach are: 1. Turning to the nature of lived experience, 2. Investigating experience as we live it, 3. Hermeneutic phenomenological reflection, 4. Hermeneutic phenomenological writing, 5. Maintaining a strong and oriented relation, and 6. Balancing the research context by considering parts and whole.<sup>20</sup> To identify thematic sentences and extract themes, Van Manen's thematic analysis approach was applied, including wholistic, selective, and line-by-line techniques.<sup>20</sup> Field and narrative notes were also used to obtain the themes. After extracting thematic expressions, similarities and relationships between them were determined by comparing the initial content of each interview to previous interviews. Accordingly, initial themes were classified into cluster themes that were merged based on their interrelationships. Sub-themes then emerged and were combined based on the relationships between cluster themes. Finally, sub-themes were merged based on their interrelationships to form the main themes. The main research question was considered during this process. Thematic analysis was conducted by a research team including one nursing PhD student, two nursing faculty member specialized in qualitative research, and one pediatric specialist. While extracting the themes, the team members exchanged perspectives, continuing this dialogue across all interviews until reaching saturation, the point at which no new findings emerged and no further changes were made to the codes.

To ensure the validity of our findings, this study adhered to van Manen's (2016) validation criteria.<sup>19</sup> To maintain phenomenological rigor and control for bias, we employed the process of epoche (bracketing) throughout the study, identifying and setting aside our preconceived notions shaped by previous encounters or experiences with the phenomenon. Van Manen emphasizes that without clear and

appropriate phenomenological questions, a phenomenological study is doomed to fail. Our research focused on core phenomenological questions aimed at understanding the lived experiences of parents caring for a child with EB. The analysis was conducted based on descriptive accounts from in-depth interviews, deliberately avoiding empirical data such as participants' opinions, beliefs, views, and interpretations. The study was grounded in primary phenomenological literature, carefully avoiding the use of questionable sources.

The study received ethical approval (code IR.MUMS.REC.1400.353) from Mashhad University of Medical Sciences' Research Ethics Committee. A written letter of introduction was obtained from the university to coordinate with Mashhad Akbar Hospital officials. All participants were informed of the study objectives and design, and provided written informed consent for participation in the study and recording of interviews. They were assured that they could withdraw from the study at any time without any effect on their childcare. Confidentiality was maintained by not mentioning the participants' names in audio recordings or interview transcripts. Each participant was assigned a unique code.

## RESULTS

The participants in this study were 10 parents, including 3 fathers and 7 mothers. The ages of children with EB ranged from 3 to 25 years. One participant had two children with the illness, while the others each had one afflicted child. Only one mother was separated from her husband and the remaining parents lived with their spouse. The type of illness in eight children was dystrophic, and in two cases it was not specified (Table 1).

The final analysis yielded four themes: "Lost and Confused about Care and Treatment", "Trapped in Endless cycle of Hardship Caring", "Inevitable Self-Isolation", and "Bitter and deteriorating family life". A summary of the main themes and sub-themes is presented in Table 2.

**Table 1:** Characteristics of the Participants

No.	Relation to child	Parent age (year)	Number of children with EB <sup>a</sup>	Child age (year)	Child sex	Father and Mother's Relation	EB type	Interview location
1	Father	53	1	22	Boy	Cousin	Not checked	Mashhad Akbar Hospital
2	Mother	40	1	16	Boy	Cousin	Dystrophic	Mashhad Akbar Hospital
3	Mother	57	1	25	Girl	Not related	Dystrophic	Participants' home
4	Mother	50	2	23 14	Girl Boy	Cousin	Dystrophic	Participants' home
5	Mother	29	1	3	Boy	Distant relative	Dystrophic	Mashhad Akbar Hospital
6	Mother	42	1	14	Boy	Not related	Not checked	Mashhad Akbar Hospital
7	Father	43	1	14	Girl	Cousin	Dystrophic	Mashhad Akbar Hospital
8	Mother	47	1	14	Girl	Not related	Dystrophic	Mashhad Akbar Hospital
9	Mother	35	1	9	Boy	Not related	Dystrophic	Participants' home
10	Father	40	1	4	Boy	Not related	Dystrophic	Participants' home

<sup>a</sup>EB: Epidermolysis Bullosa

**Table 2:** The summary of sub-themes and themes

Sub-themes	Themes
Perplexity on the vague path of care Lost hope	Lost and confused about care and treatment
Endless hardship and adversity in caregiving Profound sorrow over perceiving the child's distress and frustration	Trapped in endless cycle of hardship caring
Selective social withdrawal Imprisoned by caring for the child	Inevitable self-isolation
Family on the verge of instability and collapse Living in the shadow of constant unhappiness and despair	Bitter and deteriorating family life

### *1. Lost and Confused about Care and Treatment*

One of the themes that emerged from parents' descriptions of their experiences caring for their children with EB was "Lost and Confused about Care and Treatment". The lack of diagnosis in the early days after birth caused confusion for the parents. Due to the lack of diagnosis or lack of receiving training from the healthcare providers, they were confused in caring for the child. Some of them, due to receiving incorrect information intentionally or inadvertently from the healthcare providers, expected the child's

recovery for several years. This theme itself has two subthemes.

#### *1.a. Perplexity on the Vague Path of Care*

Parents were sent home with his/her child without receiving proper training or adequate training on how to provide care. They took the responsibility of taking care of their child at home without proper knowledge and guidance. This situation shows the feeling of loneliness, confusion, and helplessness in caring for a child with EB. They resorted to trial and error and tested different care

methods in this difficult path. In this regard, one of the parents said:

*“They discharged us and sent us home without knowing how to take care of our child. We didn’t know what to do with the wounds on their bodies. The bandages were sticking and we didn’t know how to remove them. We confusedly tried everything our relatives suggested. We were doing it, hoping that something might work.” (P4)*

### *1.b. Lost Hope*

Parents, unaware of the true nature of their child’s illness, clung to hope for their future and potential recovery. Initially, they were given false reassurance that the disease would improve as the child grew. This unrealistic hope served as a tool to keep parents motivated in caring for their child. However, as time passed without improvement, parents faced the truth that this hope was merely a well-intentioned deception. In this regard, a mother reported:

*“They told us not to take the child to the doctor too much. They recommended, “Don’t bother the kid. When this child grows up and reaches maturity, he will get better.” As the child grew older, his condition did not improve. When we took him to the doctor, he said that years ago we gave you optimistic information so that you don’t lose hope or stop caring for your child.” (P2)*

### *2. Trapped in Endless Cycle of Hardship Caring,*

This theme points to the constant and repeated suffering and helplessness endured by parents of children with this disorder. Faced with many painful symptoms associated with the illness, parents experience unlimited hardship and anguish. This theme has two sub-themes: “Endless hardship and adversity in caregiving” and “Profound sorrow over perceiving the child’s distress and frustration”.

#### *2.a. Endless Hardship and Adversity in Caregiving*

Caring for children with EB extends beyond simple caregiving and is accompanied by numerous hardships and challenges.

Parents must remain vigilant on this journey, undertaking constant care of their child. Frequent sleepless nights and the need to soothe the child throughout the night, coupled with the necessity to provide care in all aspects of the child’s life, such as wound management, lead to fatigue and hardship for the parents. In this regard, one of the parents stated:

*“Caring for these children is incredibly challenging. I have to be alert to everything at all times, from feeding to changing bandages and tending to wounds. Some nights I’d be up until dawn because the child would cry, and I had to hold them. Sometimes, I feel like I’m on the verge of collapse from sheer exhaustion.” (P8)*

#### *2.b. Profound Sorrow Over Perceiving the Child’s Distress and Frustration*

Parents experience deep sorrow and grief as they witness their child’s suffering and limitations. They observe their child’s physical disabilities and constraints while being aware of their mental capabilities. This contradiction between the child’s mental ability and physical disability is painful for the parents. Parents find themselves in a situation where their child’s suffering and disability affect their own spirit and psyche, yet they feel powerless to alleviate this suffering. One of the fathers stated:

*“My child’s fingers are fused together. When I see that he can’t do the things he wants to do, it breaks my heart. His mind is like other children, but his body doesn’t allow it. Sometimes, I feel like my hands are tied, and I can’t do anything to reduce his suffering. The emotional and physical pain he endures is tearing me apart inside.” (P1)*

### *3. Inevitable Self-isolation*

Parents caring for a child with EB spend much of their life at home, avoiding social situations when possible. This is sometimes by choice and sometimes unavoidable. This theme includes two sub-themes: “Selective social withdrawal” and “Imprisoned by caring for the child”.

### 3.a. Selective Social Withdrawal

Parents feel stressed by facing people's questions about their child's condition and believe that people's stares are hurtful for them and their children. They are bothered by their child being singled out and judged by others. One mother who had two children affected by EB stated:

*"I get very stressed when we go out with the kids. People stare and ask stuff and it upsets me and the kids, and I feel bad about the whole situation". (P4)*

They worry about their child getting injured if they participate in society or interact with relatives. Therefore, they avoid communication with relatives and society. One of the parents said:

*"We don't go out much and we don't socialize with others. If we go out or visit relatives' homes and my child plays with other children, their hand or foot might get crushed. That's why we don't interact much with others". (P5)*

### 3.b. Imprisonment Due to Caring for the Child

The constant and uninterrupted care required for a child with EB severely impacts the parents' lives, to the extent that they have no time for social interactions or leaving the house. They find themselves in a situation where all their time and energy are consumed by caring for their child as if they are confined and enclosed in an invisible prison. A mother shared her experience:

*"I have to watch over my child every moment and can't leave them alone even for a short time. I can't go out for errands or even visit my friends. My friends or sisters say, 'Come, let's go for a walk to change your mood,' but I can't go with them. It's like I'm imprisoned at home because I can't leave my child alone even for a few hours." (P4)*

### 4. Bitter and Deteriorating Family Life

The lifestyle and life path of these caregivers are out of the routine. One parent must always be at the service of their sick child. Due to the severity of the child's disease

and the constant pain of these children, parents are hopeless and it seems as if happiness has been removed from their lives. This theme has two sub-themes including "Family on the verge of instability and collapse" and "Living in the shadow of constant unhappiness and despair".

#### 4.a. Family on the Verge of Instability and Collapse

When a family has a child with EB, all parental attention, especially the mother's, becomes singularly focused on that child. This intense caregiving concentration leads to an unintended neglect of daily family responsibilities and leaves little time to express affection towards the spouse and other children, which can destabilize the foundations of family life. Furthermore, in some cultures, the birth of such a child is attributed to the mothers, potentially placing an additional psychological burden on their shoulders. One mother shared her experience:

*"I dedicate all my time to my son. Sometimes, I don't cook for up to 24 hours, which upsets my husband. Overall, I don't have time to show affection to my other children or my spouse. Since this child was born, my husband has become indifferent towards me and thinks I'm to blame for our child's illness." (P9)*

Parents are forced to be constantly traveling for multiple and repeated visits by doctors with different specialties, and they endure a great deal of hardship along this path. Therefore, a number of parents have lost their jobs or changed their jobs. On this matter, one of the mothers said:

*"I devote all my time to this child. I'm constantly traveling back and forth for the treatment with various doctors, and I've lost both my job and my personal life because of it". (P3)*

Some families have been forced to relocate. The need for better access to specialized medical centers and providing more suitable conditions for childcare compels the parents to move to cities with better medical facilities.

In this regard, one of the parents stated:

*“We used to live in a village. It was an hour’s drive from the city to our village. When our child was about a year and a half old, we moved from our village to another city. I thought the child was having a really hard time there, so we needed to come to the city to be close to all the facilities. That’s why we left.” (P8)*

#### *4.b. Living in the Shadow of Constant Unhappiness and Despair*

The experience of parents caring for a child with EB is characterized by a gradual loss of hope as they confront the progressive nature of this condition. Initially hopeful for improvement with age, parents instead face worsening symptoms and the realization that even international medical expertise cannot offer a cure. Understanding these realities leads to a profound sense of despair and hopelessness about their child’s future. One of the fathers shared his experience:

*“In the early months after our child was born, we were hopeful that their condition would improve with age. Unfortunately, as our child grew older, their problems only worsened. We eventually came to the devastating realization that even seeking treatment abroad wouldn’t offer a cure. We’ve lost all hope for our child’s future”. (P10)*

The lives of these parents are accompanied by a constant sense of unhappiness. This state goes beyond temporary sadness or passing grief, evolving into a permanent and pervasive condition in their lives. Parents find themselves in a situation where joy and vitality have departed from their lives, replaced by a persistent feeling of sadness. One participant stated:

*“This disease has filled our lives with sorrow and unhappiness. We’re sad most of the time. Even during meals, when we see our son can’t eat, my husband and I can’t eat either. This just makes us sad. It’s as if this illness has taken the pleasure out of everything, even a simple meal.” (P4)*

## **DISCUSSION**

The findings of this study offered valuable insights into the experiences of family caregivers from caring for children with EB over an extended period. The main themes of the study are the following: “Lost and confused about care and treatment”, “Trapped in endless cycle of hardship caring”, “Inevitable self-isolation”, and “Bitter and deteriorating family life”. The results revealed that parents of children with EB experience many stresses in physical, emotional-psychological, social, and financial domains. Caring for these children involves great and constant difficulties and burdens. The results of this study are similar to those of other studies and show that the parents of children with chronic disease face considerable challenge.<sup>13, 21, 22</sup>

One of the themes that emerged from the study is “lost and confused about care and treatment”. Our study findings revealed confusion and uncertainty regarding the care and treatment of EB, particularly in the initial days following the child’s birth. Insufficient information about the disease, treatment, prognosis, and doubts about the treatment, were among the major challenges faced by these caregivers. Parents described feeling bewildered when trying to find solutions for their children. Some of them reported that some members of the healthcare providers gave them false hope about the future of the disease and the possibility of recovery, which was probably due to their lack of knowledge and information. Other studies also confirm the results of our research. In two studies, participants have stated that many healthcare providers do not fully understand EB, so they are not able to provide immediate and accurate care information, and they should be informed about the disease and trained about this disease and its complexities. As a result, family caregivers have experienced fear and distress while caring for their children.<sup>9, 23</sup> In another study, parents had not received training on how to care for their children and were confused in this regard. They were also



dissatisfied with the lack of knowledge and skills of healthcare providers concerning EB.<sup>24</sup>

Another theme that emerged from this study is “trapped in endless cycle of hardship caring”. Witnessing a child’s ongoing suffering devastates parents. Repeated skin and bodily injuries, recurring esophageal blockages, and similar incidents inflict immense emotional damage. Other worries about developmental delays, potential harm at school, social stigma, and news of other children’s deaths increase the hardships related to caregiving. This result is in the same line with previous research findings. One study identified the constant worry and grief of parents caring for children with EB as a major challenge.<sup>25</sup> Other studies, stated that these patients needed complex and long-term care.<sup>9</sup> The care burden is high in parents. This burden increases based on the type and severity of the disease and the level of the child’s body involved.<sup>10, 26</sup> These findings indicate that the immense pressure of providing care can exceed the ability of parents, especially mothers who typically shoulder the main responsibility. This can cause deep and enduring grief for parents.<sup>8</sup>

The study findings also highlighted “inevitable self-isolation” as a prominent theme. The heavy burden of caring for a child with EB severely isolates the caregivers, especially mothers, from the outside world. The constant duties of caring about wounds, bathing, feeding, and providing round-the-clock care leave little time for mothers to care for themselves or other family members. They also avoid going out in public or seeing relatives to shield themselves and their children from intrusive stares and invasive questions. The results of this study are consistent with those of previous research. One study showed that parents of these patients often experienced loneliness and social isolation.<sup>9</sup> Another study has found that the hands-on nature of caregiving duties, which allow for little or no breaks, severely limits the parents’ ability to work or partake in leisure activities.<sup>22</sup>

Another major theme emerging from this study is “bitter and deteriorating family life”.

According to our findings, the birth of a child with EB led to heightened emotional strain between parents. Mental and physical health issues become more common within families. The family’s life path changes due to the need for frequent commuting and the family’s future is in jeopardy. One study revealed that caring for a child with EB profoundly impacts the family’s physical and mental health. Family members often experience emotional distress and are overwhelmed by the physical demands of care.<sup>9</sup> Another study reported that parents’ physical and emotional communication decreased due to the child’s disease.<sup>8</sup> Parents express a reluctance to have more children in the future due to the challenges posed by the disease.<sup>8, 10</sup> Additional studies indicate parents of patients with EB report low life satisfaction and quality of life.<sup>26, 27</sup>

Ultimately, the findings of this study are in the same line with other research, showing that parents of children with EB endure profound emotional, physical, psychological, and social challenges. These caregivers are “hidden patients,” requiring support programs from family, community organizations and government agencies, which can mitigate their suffering.

Regarding the strengths of the study, it provides valuable insights into the experiences and challenges faced by caregivers of individuals with EB. It highlights the areas for improving support services, developing educational resources, or implementing interventions to address the specific needs of the caregivers. Regarding the limitations of this study, it should be noted that only three fathers participated as most interviews were conducted at one health center where mothers typically accompanied their children. Additionally, the phenomenological nature of this study inherently limits the generalizability of its findings. As such, the results should be interpreted cautiously and may only be applicable to similar contexts.

In clinical practice, these results highlight opportunities for healthcare professionals to

better assist family caregivers of patients with EB. Providers should recognize the caregivers' need for ongoing support throughout their challenging journey, including help with establishing short- and long-term goals. Medical and nursing educators can use these findings to develop EB educational programs, expanding the providers' knowledge to better aid families. Some countries offer centralized support services for parents of children with rare diseases; implementing similar care services in countries like Iran could significantly improve the caregivers' quality of life. Educating healthcare teams about EB and counseling parents on proper disease management can reduce uncertainty. Connecting with other families and joining peer support groups alleviates difficult feelings and allows the parents to share caregiving ideas. Parents and children should be taught to accept the disease and find empowerment through these connections. It's crucial for parents to understand that neither is to be blamed for their child's condition and that caregiving requires support from both parents. Genetic counseling and testing can further reduce psychological strain on the family.

## **CONCLUSION**

The relentless physical burden of caregiving, compounded by bearing witness to their child's suffering, entraps parents in a cyclical pattern of adversity and anguish. Facing social isolation and judgment, strained family relationships, loss of jobs and instability, these parents experience constant worry, grief, and hopelessness. Ultimately the incurable, devastating nature of this illness permeates all aspects of family life, leaving caregivers with unremitting stress and despair. Healthcare providers must address EB-related challenges by developing comprehensive support programs, including home care, telehealth, and community education. Advocacy and holistic approaches are essential to reduce caregiver isolation and support families. Future research should investigate caregiver coping strategies, mental

health impacts, and cultural influences.

## **Acknowledgment**

The authors appreciate the parents who generously shared their experiences.

## **Authors' Contribution**

HKH, ZSM and HKM contributed to the conceptualization and design of this study. The data collection was conducted by HKH, with assistance from ZSM, HKM, and HRK. The data analysis and interpretation were carried out collaboratively by HKH, ZSM, HKM, and HRK. HKH drafted the initial manuscript. All authors critically reviewed, revised, and approved the final version of the manuscript for publication. All authors take responsibility for the integrity of the data and the accuracy of the data analysis. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

## **Funding**

This study was derived from a doctoral dissertation funded by Mashhad University of Medical Sciences (project code 4001372).

**Conflict of Interest:** None declared.

## **Declaration on the use of AI**

During the preparation of this work, the authors used Claude AI by Anthropic to enhance textual clarity and grammatical precision. The authors subsequently reviewed and edited the content, assuming full responsibility for the publication.

## **REFERENCES**

- 1 Plewig G, French L, Ruzicka T, et al. Braun-Falco's Dermatology. Berlin: Springer Berlin Heidelberg; 2022.
- 2 Mauritz PJ, Bolling M, Duipmans JC, Hagedoorn M. Patients' and parents'

- experiences during wound care of epidermolysis bullosa from a dyadic perspective: a survey study. *Orphanet Journal of Rare Diseases*. 2022;17:313.
- 3 Pfindner EG, Lucky AW. Dystrophic epidermolysis bullosa. In: Adam MP, Feldman J, Mirzaa GM, et al (eds). *GeneReviews*. Seattle (WA): University of Washington; 2018.
  - 4 Watkins J. Diagnosis, treatment and management of epidermolysis bullosa. *British Journal of Nursing*. 2016;25:428-31.
  - 5 Prodinge C, Diem A, Bauer JW, Laimer M. [Mucosal manifestations of epidermolysis bullosa: Clinical presentation and management]. *Hautarzt*. 2016;67:806-15.
  - 6 Prodinge C, Reichelt J, Bauer JW, Laimer M. Epidermolysis bullosa: Advances in research and treatment. *Experimental Dermatology*. 2019;28:1176-89.
  - 7 Pelentsov LJ, Laws TA, Esterman AJ. The supportive care needs of parents caring for a child with a rare disease: a scoping review. *Disability and Health Journal*. 2015;8:475-91.
  - 8 Chateau AV, Blackbeard D, Aldous C. The impact of epidermolysis bullosa on the family and healthcare practitioners: a scoping review. *International Journal of Dermatology*. 2023;62:459-75.
  - 9 Wu YH, Sun FK, Lee PY. Family caregivers' lived experiences of caring for epidermolysis bullosa patients: A phenomenological study. *Journal of Clinical Nursing*. 2020;29:1552-60.
  - 10 Stefano SDE, Grassi FS, Lalatta F, et al. Family burden of children suffering from epidermolysis bullosa. *Italian Journal of Dermatology and Venereology*. 2021;156:580-7.
  - 11 Holliday AM, Quinlan CM, Schwartz AW. The hidden patient: The CARE framework to care for caregivers. *Journal of Family Medicine and Primary Care*. 2022;11:5-9.
  - 12 Martínez-Ripoll JM, García-Domingo M, de la Fuente Robles YM. Epidermolysis Bullosa in Spain: A Qualitative Analysis of Its Social Impact on Families With Diagnosed Minors. *Health Expectations*. 2024;27:e14128.
  - 13 Chogani F, Parvizi MM, Murrell DF, Handjani F. Assessing the quality of life in the families of patients with epidermolysis bullosa: The mothers as main caregivers. *International Journal of Women's Dermatology*. 2021;7:721-6.
  - 14 Forghani SF, Jahangiri R, Ghasemi F, et al. Economic Burden of Epidermolysis Bullosa Disease in Iran. *Medical Journal of the Islamic Republic of Iran*. 2021;35:146.
  - 15 Eghtedar S, Jasemi M, Habibzadeh H. The role of beliefs and psychological factors in caring of patients with cancer: the lived experiences of informal caregivers. *Holistic Nursing Practice*. 2021;35:248-56.
  - 16 Rahnema M, Khoshknab MF, Maddah SSB, et al. Religion as an alleviating factor in Iranian cancer patients: a qualitative study. *Asian Pacific Journal of Cancer Prevention*. 2015;16:8519-24.
  - 17 Ahmadi F, Khodayarifard M, Zandi S, et al. Religion, culture and illness: A sociological study on religious coping in Iran. *Mental Health, Religion & Culture*. 2018;21:721-36.
  - 18 Davari M, Haycox A, Walley T. The Iranian health insurance system; past experiences, present challenges and future strategies. *Iranian Journal of Public Health*. 2012;41:1-9.
  - 19 Van Manen M. *Phenomenology of Practice. Meaning-Giving Methods in Phenomenological Research and Writing*. London/New York: Routledge; 2016.
  - 20 Van Manen M. *Researching lived experience: Human science for an action sensitive pedagogy*. 2nd ed. New York: Routledge; 2016.
  - 21 Kish AM, Newcombe PA, Haslam DM. Working and caring for a child with chronic illness: A review of current literature. *Child Care Health and Development*. 2018;44:343-54.

- 22 Kearney S, Donohoe A, McAuliffe E. Living with epidermolysis bullosa: Daily challenges and health-care needs. *Health Expectations*. 2020;23:368-76.
- 23 Martin K, Geuens S, Asche JK, et al. Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based guidelines. *Orphanet Journal of Rare Diseases*. 2019;14:133.
- 24 Chateau AV, Aldous C, Dlova N, Blackbeard D. 'It breaks my heart': Healthcare practitioners' caring for families with epidermolysis bullosa. *Health SA*. 2023;28:2355.
- 25 Ireland CJ, Pelentsov LJ, Kopecki Z. Caring for a child with Epidermolysis Bullosa: a scoping review on the family impacts and support needs. *Wound Practice & Research*. 2021;29:86-97.
- 26 Bruckner AL, Losow M, Wisk J, et al. The challenges of living with and managing epidermolysis bullosa: insights from patients and caregivers. *Orphanet Journal of Rare Diseases*. 2020;15:1.
- 27 Mączik D, Kowalska-Dąbrowska M. The need of social support, life attitudes and life satisfaction among parents of children suffering from epidermolysis bullosa. *Dermatology Review*. 2015;102:211-20.