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Parental awareness of oral health in children with epidermolysis bullosa in Indonesia

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ABSTRACT

Background: *Children affected by epidermolysis bullosa (EB) have serious oral conditions that may affect their quality of life. It is the parents' crucial role to maintain the oral health of children with EB.* ***Purpose:*** *This study aims to determine the crucial role of parents in maintaining the oral health of children with EB. It also aims to assess parents' oral health knowledge and perceptions of their children's oral health-related quality of life.* ***Methods:*** *Conducted at Yayasan Dystrophic Epidermolysis Bullosa Research Association, Indonesia, this descriptive study employed a questionnaire translated through cross-cultural adaptation and the Caregiver Perception Questionnaire using a Likert scale.* ***Results:*** *Among the 18 respondents, parental knowledge appeared favorable. Regarding the oral symptoms dimension, 56% of children were in the excellent category, 28% in the moderate category, and 17% in the poor category. In terms of functional limitations, 50% were in the suitable category, 39% were moderate, and 11% were poor. In the emotional state dimension, 78% of participants were in the excellent category, whereas 22% were in the moderate category. In the social conditions dimension, 89% were in the excellent category and 11% in the moderate category.* ***Conclusion:*** *Although parents demonstrated an understanding of oral health care for EB, challenges in implementation emerged.*

Keywords: *children with EB; knowledge and perception; oral health; parent*
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INTRODUCTION

Epidermolysis bullosa (EB) is a rare genetic disorder characterized by skin and mucosal fragility, leading to the easy formation of blisters.[1–3] This condition can be detected at birth. The fragility of the skin in patients with EB is caused by mutations in the structural proteins of the skin, resulting in separation at the basement membrane between the dermis and epidermis.[4] EB can be inherited in either a dominant or recessive pattern from the parents.[3,5–7]

Patients with EB present with clinical symptoms in the form of blisters that initially appear on the skin of the extremities due to friction, trauma, or spontaneous contact. Subsequently, blisters may develop in other areas of the skin frequently exposed to friction, such as the eyes, mouth, throat, digestive tract, or bladder.[1,3,5,6,8] These clinical symptoms may manifest throughout the oral cavity, resulting in wounds that interfere with its normal development. Oral manifestations include conditions such as ankyloglossia, tongue atrophy, destruction of the buccal and vestibular sulci, tongue depapillation, palatal rugae atrophy, and perioral wounds that lead to scar tissue formation and ultimately to microstomia.[1,9–11]

Routine oral and dental health maintenance is challenging for patients with EB due to oral clinical symptoms and reduced hand function caused by wounds and scar tissue formation, which can result in pseudosyndactyly.[12–14] As a consequence of these symptoms and functional limitations, specialized approaches and treatments are required to maintain the oral and dental health of children with EB.[15,16]

The prevalence of dental caries and periodontal disease is relatively high in children with EB due to poor oral health.[12,17,18] Compared with healthy children, those with

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EB tend to have more cavities and plaque. Therefore, maintaining oral health in children with EB is crucial. These children and their parents are typically provided with knowledge and instructions on maintaining routine dental and oral health, and parents are also encouraged to accompany and supervise their children with limited mobility.[1] However, due to skin fragility and the severity of EB symptoms, parents may sometimes fear causing blisters while cleaning the mouth, which can lead to nonadherence to oral health instructions.[12]

Collaboration among patients, parents, and dentists is essential to achieve and maintain adequate dental and oral health in children with EB. To date, no study in Indonesia has explored parents' knowledge of oral health and their perceptions of their children's oral health-related quality of life. This study aimed to assess parental knowledge of their children's oral health and their perceptions of the oral health–related quality of life in children with EB.

MATERIALS AND METHODS

The Universitas Padjadjaran Research Ethics Committee approved the study (Document Number 528/UN6.KEP/EC/2023), which was conducted between May and June 2023. Written consent was obtained from the parents prior to the study. This was a quantitative descriptive study using a survey approach. The population consisted of parents of children with EB who were part of the Dystrophic Epidermolysis Bullosa Research Association (DEBRA) community in Indonesia. The sample was obtained using a nonprobability sampling technique, specifically total population sampling, due to the small population size. Parental knowledge was assessed using a questionnaire validated by Colovic et al.[12] and adapted from English to Indonesian by the Language Center, Faculty of Cultural Sciences, Universitas Padjadjaran. The questionnaire underwent a cross-cultural adaptation process.

Parental perceptions were evaluated using the Parental Caregiver Perception Questionnaire 16 (P-CPQ 16), which assesses the child's oral health-related quality of life. The P-CPQ 16 includes sixteen items across four domains: oral symptoms, functional limitations, emotional well-being, and social well-being. Response options were as follows: 0 = never, 1 = rarely, 2 = sometimes, 3 = often, and 4 = very often. Higher scores indicate poorer quality of life. The questionnaire was adapted and tested for reliability and validity in a 2021 study by Indriyanti et al.[19], with a Cronbach's α reliability coefficient of 0.843. All data were analyzed using descriptive statistical analysis.

RESULTS

The total study sample consisted of 19 individuals from various regions in Indonesia. However, one parent withdrew from the study due to the deterioration of their child's health. As a result, the total number of respondents was 18 parents of children with EB. The characteristics of the respondents based on gender and their relationship with the child are presented in Table 1. Although the study initially intended to include both mothers and fathers, all participants were mothers, with the majority (44%) having completed senior high school. Among the types of EB, EB simplex (EBS) was the most prevalent, affecting 55% of the children.

Table 2 describes the oral health conditions of the children with EB. Most children had teeth, except for three aged 0–12 months. Among the respondents, 61% reported that their children had experienced dental pain for various reasons, including cavities, fragile teeth, loose teeth, excessive candy consumption, hard foods, irregular brushing habits, and frequent bottled milk intake. Additionally, 72% had experienced various oral conditions such as fungal thrush on the tongue, canker sores, swollen and bleeding gums, mucosal lesions, and blisters.

An overview of the parents' understanding and practices regarding dental care is also presented in Table 2. Fifty percent reported receiving advice to consult a dentist. Only 17% of the children had a designated regular dentist. Regarding the reasons for dental visits, only 5% scheduled routine check-ups, whereas 67% visited the dentist in response to specific dental issues.

Table 3 presents data on oral hygiene habits among the sample group. Parental knowledge of oral hygiene practices intended to support their children's oral health revealed that a substantial proportion (89%) used toothbrushes and toothpaste as their primary oral

Table 1. Patient characteristics

Characteristics of Respondents	Frequency (n)	Percentage (%)
Highest Education Level		
Elementary school	1	6
Junior high school	0	0
Senior high school	8	44
Diploma	4	22
Bachelor's degree	4	22
Others	1	6
Characteristics of Children	**Frequency (n)**	**Percentage (%)**
Age Range of Children		
0–12 months	4	22
1–5 years	6	33
6–13 years	5	28
14–19 years	3	17
Type of Epidermolysis Bullosa (EB) Afflicted		
EB simplex	10	55
EB junctional	2	11
Dominant dystrophic EB	1	6
Recessive dystrophic EB	5	28
EB kindler	0	0

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Table 2. Children's oral health conditions and parental knowledge about dental care

Oral Health Conditions	Frequency (n)	Percentage (%)
Presence of Teeth		
Yes	15	83
No	3	17
Children's Experience of Dental Pain		
Yes	11	61
No	7	39
Children's Experience of Oral Diseases		
Yes	13	72
No	5	28
Parental Difficulties in Oral Health Care		
Yes	11	61
No	7	39
Reasons for Parental Difficulties		
Lack of understanding in oral health care	1	6
Insufficient tools and materials	4	22
Child's unwillingness or refusal	4	22
Other reasons	2	11
Parental Knowledge about Dental Care		
Received Advice to Consult with a Dentist		
Yes	9	50
No	9	50
Child Has a Regular Dentist		
Yes	3	17
No	15	83
Reasons for Dental Visits		
Received advice on oral health care for the child	5	28
Routine check-up	1	5
Dental issues and problems	12	67
Choice of Dentist		
Private practice dentist	0	0
Nearest dental clinic	4	22
Experienced and trained dentist for children with epidermolysis bullosa	14	78
Dentist Refuse to Provide Treatment		
Yes	9	50
No	9	50
Frequency of Routine Check-up		
Every 3 months	0	0
Every 6 months	1	6
Once a year	0	0
When there is a problem	17	94
Dentist Provides Information and Training		
Yes	7	39
No	11	61
Dentist Applies Fluoride to the Child's Teeth		
Yes	7	39
No	11	61

Table 3. Parental knowledge on maintaining children's oral health

Question	Frequency (n)	Percentage (%)
Oral Hygiene Tools		
Toothbrush and toothpaste	16	89
Dental floss	1	6
Mouthwash	0	0
All of the mentioned	1	6
Use of Mouthwash		
Fluoride-containing mouthwash	1	6
Chlorhexidine-containing mouthwash	1	6
Herbal mouthwash	2	11
Do not use mouthwash	14	78
Use of Plaque Identification Products		
Yes	2	11
No	16	89
Frequency of Brushing Per Day		
Once a day	2	11
Twice a day	11	61
More than twice a day	1	6
Not every day	4	22
Brushing at Appropriate Times		
Yes	9	50
No	9	50
Rinsing Mouth with Water After Eating		
Yes	12	67
No	6	33
Toothbrush Head Size		
Small	14	78
Standard	3	17
Not sure	1	5
Bristle Hardness		
Soft	12	67
Medium	4	22
Hard	0	0
Not sure	2	11
Use of Specialized Toothbrush		
Yes	6	33
No	12	67
Toothbrush Replacement Time		
Every 2–3 months	10	56
Every 6 months	1	5
Once a year	0	0
When bristles are damaged	7	39
Fluoride-Containing Toothpaste		
Yes	14	78
No	4	22
Number of Meals Per Day		
Three times a day	14	78
Four times a day	3	17
Five times or more per day	1	5
Feeding Duration		
10 minutes	6	33
20–30 minutes	9	50
More than 30 minutes	3	17
Types of Consumed Food		
Solid and no sharp	8	44
Soft and tender	10	56
Sweet Food Consumption		
Once a day	5	28
Twice a day	7	39
Three or more times a day	4	22
No sweet consumption	2	11
Consumption of Sugar-Containing Supplements		
Yes	5	28
No	13	72
Awareness of Sugar-Free Medication and Supplements		
Yes	2	11
No	16	89

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hygiene tools. Only a minority (11%) reported using plaque identification products. These findings highlight the predominant use of traditional brushing methods, with relatively low adoption of additional oral hygiene aids such as mouthwash or plaque-disclosing products. Regarding brushing frequency, 61% of parents reported brushing their children's teeth twice daily, and 50% ensured brushing occurred after breakfast and before bedtime. For toothbrush head size, 78% of parents used a small-sized toothbrush. In terms of bristle hardness, 67% used toothbrushes with soft bristles.

Insights into parental knowledge regarding their children's food and supplement consumption are also presented in Table 3. Most parents (78%) reported that their children consumed three meals daily, typically lasting between 20 and 30 minutes. A nearly equal distribution was observed in the types of food consumed, with 56% of parents stating that their children ate soft and tender foods. Regarding sweet food intake, 39% reported consumption twice daily, whereas 11% reported no consumption of sweet foods. Finally, only 11% of parents were aware of sugar-free medications and supplements.

Table 4 summarizes parents' perceptions of the quality of life in children with EB in relation to oral health. Most children experienced various oral symptoms, including toothache, discomfort, bleeding gums, bad breath, and food stuck between the teeth, with varying frequencies. The majority of children faced functional limitations such as difficulty biting or chewing hard foods, slower eating of meat, and, in some cases, discomfort with hot or cold foods and sleep disruptions due to a toothache. For most children, oral health problems did not substantially affect their emotional or social well-being. However, a smaller percentage of respondents reported disruptions in these areas, albeit at a lower frequency.

Table 4 also presents four dimensions of parental perception regarding their children's quality of life. The majority of responses fell into the "good" category. Fifty-six percent of the children with EB experienced oral symptoms, 50% had functional limitations, 78% faced emotional

Table 4. Distribution of parental perceptions of the quality of life of children with EB

Quality of life dimension	Oral health related terms	Never		Rarely (1–2x/3 month)		Occasionally (>2x/3 month)		Sometimes (almost every week)		Often (every day)	
		f	%	f	%	f	%	f	%	f	%
Oral symptoms	Toothache, lip, jaw, or mouth discomfort	5	28	4	22	4	22	2	11	3	17
	Bleeding gums	8	45	6	33	0	0	2	11	2	11
	Halitosis	7	39	4	22	2	11	3	17	2	11
	Food getting stuck between teeth	5	28	4	22	4	22	1	6	4	22
Functional limitation	Difficulty biting or chewing hard food	8	44	3	17	3	17	2	11	2	11
	Taking longer to eat meat than usual	7	39	3	17	2	11	2	11	4	22
	Difficulty eating/drinking hot/cold foods	9	50	2	11	3	17	1	5	3	17
	Sleep disorder due to toothache	11	61	4	22	2	11	0	0	1	6
Emotional wellbeing	Frustration/irritation due to dental problems	10	56	4	22	3	17	0	0	1	5
	Embarrassment due to dental conditions	13	72	3	17	2	11	0	0	0	0
	Anxiety/fear of teeth being different from other children	13	72	2	11	2	11	1	6	0	0
Social wellbeing	Reluctance to speak	15	83	1	6	2	11	0	0	0	0
	Refusal to smile/laugh	13	72	3	17	1	6	1	6	0	0
	Difficulty concentrating in learning	13	72	3	17	2	11	0	0	0	0
	Refusal to play	15	83	1	6	2	11	0	0	0	0
	Absenteeism from school	12	67	5	28	1	5	0	0	0	0

Quality of life related to oral health	Oral symptoms	Functional limitations	Emotional well-being	Social well-being
Good	10	9	14	16
Moderate	5	7	4	2
Poor	3	2	0	0

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challenges, and 89% encountered social issues. These findings provide insight into how EB impacts quality of life related to oral health, as perceived by parents, across different dimensions of well-being.

DISCUSSION

The study reveals that children with EB exhibit dental growth that is largely unaffected by oral symptoms. However, they experience higher incidences of dental issues such as tooth decay, plaque accumulation, and periodontal diseases compared with healthy children.[12] In this study, most children suffer from toothache and oral diseases, exacerbated by cavities, brittle teeth, and the consumption of hard foods. The prevalence of oral mucosal blisters and mouth ulcers aligns with EB's characteristic fragile mucosal skin.[15,16,20] In this study, the prevalence of mouth ulcers was consistent with the majority of children experiencing the EBS type.

A substantial number of parents expressed difficulties in maintaining the oral health of children with EB. The most frequently chosen reasons were inadequate tools and materials, such as dental floss, mouthwash, plaque identification products, and specialized toothbrushes, as well as the child's refusal to cooperate. Some parents also feared cleaning their child's teeth and mouth due to the risk of causing blisters. This aligns with the findings of Colovic et al.,[12] who stated that some parents were afraid to clean their child's mouths for fear of causing blisters.

This study also revealed that a substantial number of parents had not received information or training from dentists regarding oral health care for their children. This lack of knowledge could be a contributing factor to parents' fear of managing their child's oral hygiene. Most parents did not have a regular dentist and only visited a dentist when their child had dental or oral issues. Similar results were reported in the study by Colovic et al.,[12] where 52.9% of parents only brought their child to a dentist when there was a problem and did not have a regular dentist.

Krämer et al.[15] stated that the key to maintaining oral health in children with EB is to provide parents with oral health care instructions, regularly monitored through preventive dental programs, and to include tooth cleaning and fluoride therapy during each routine visit. Nearly all parents (78%) in this study expressed a preference for visiting dentists who are experienced and trained in handling children with EB.[16] This preference may be driven by the experiences of some parents who were rejected by dentists unwilling to treat children with EB. Similar findings were observed in the study by Colovic et al., where 47.1% of parents reported limited access to dentists due to the latter's lack of knowledge and experience in treating children with EB.

Krämer's et al.[15] study highlighted that preventive oral health care can be achieved through toothbrushing, rinsing with water after meals, using plaque identification tablets, and scaling by dentists. In this study, all children brushed their teeth using toothbrushes and toothpaste. Adjuvant therapy for the oral cavity in patients with EB may include chlorhexidine mouthwash, which is effective against Candida, and fluoride mouthwash, which helps control dental caries. Toothbrushes can be optimized by selecting the smallest size with a small head and soft bristles, soaking the brush in warm water to soften it, using a specialized toothbrush, and providing parental assistance to reduce the risk of tissue damage.[15,16] Most children also rinsed their mouths after meals and when unable to brush their teeth. When toothbrush use is not feasible, parents can wrap their fingers with wet gauze and gently clean the tooth surfaces.[12]

The quality of life of children with EB is closely related to their food consumption and nutritional status. These children may suffer from malnutrition due to decreased food intake and increased nutritional needs.[21] The nutritional requirements of patients with EB are greater than those of healthy individuals, primarily because their bodies need more energy for wound healing.[15,21] According to Colovic's study, individuals with EB spend approximately 150 minutes eating each day, typically consuming soft, tender, and sticky foods.[12] In this study, most parents were unaware of sugar-free medications and supplements, but did not provide sugar-containing supplements to their children. However, more children with EB consumed sweet foods than children without EB. High-calorie foods and high-sugar supplements may lead to rapid development of dental caries and early tooth damage. Dietary modifications aligned with preventive dental and oral health care programs need to be initiated as early as possible, while also optimizing the nutritional status of patients with EB.[15,16] These dietary modifications may include reducing the frequency of snacking between meals, limiting the intake of cariogenic foods, increasing the consumption of low-sugar and high-protein alternatives, and restricting sweet food intake to once daily after main meals.[12]

This study also demonstrated how parents perceive the oral health–related quality of life in children with EB. These results appear more favorable than those reported in Marty et al.'s study,[22] which noted that children with EB experienced oral pain limiting activities such as speaking, eating, and swallowing. Generally, the oral health–related quality of life in children with EB is reduced due to pain and functional limitations caused by the disease.[22,23] However, in this study, fewer children experienced difficulty biting or chewing hard foods, eating slowly, consuming hot or cold items, or sleep disturbances caused by a toothache. Mauritz's study indicated that EB affects patients' quality of life by reducing their physical, social, and psychological functioning.[24] The findings of this study are more favorable compared with the social–emotional well-being scores reported in Marty et al.'s study, which had an average score of 13.3, below the normative value of 24.5.[22]

The findings of this study may be influenced by the fact that the majority of the children were in the 0–5-year age

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range. As such, these children may not be able to express their emotions accurately to their parents. According to Mauritz's study, children and parents with EB generally use coping mechanisms such as acceptance (e.g., "I can cope with this illness") and positive affirmations (e.g., "I hope this illness will go away") to address their emotional state. By doing so, patients can maintain hope and build the determination needed to cope with their incurable condition.[24] Parental involvement is crucial in implementing emotional coping strategies for children, especially younger children who require more specific approaches.

This study has limitations due to its small sample size, which was caused by the limited number of patients with EB associated with the DEBRA Indonesia Foundation, not all of whom were part of the community group. Moreover, EB is often misdiagnosed due to the complexity of establishing a diagnosis in children. The condition of the children's oral cavity is unknown, as intraoral examinations were not conducted; therefore, an assessment of the children's oral health in relation to parental knowledge could not be obtained. These limitations should be considered in future research. Further studies should involve more detailed measurement tools and direct involvement of children to obtain more accurate data regarding the oral health status of children with EB and their perceptions. Education about oral health care for children with EB should also be provided by experts to both children and parents.

In conclusion, this study indicates that while most parents are aware of the importance of maintaining their children's oral health with EB, they encounter practical difficulties in implementing effective care. As a result, practical oral health care for children with EB requires vital collaboration between the child, parents, and dentists, with regular supervision. Assessing quality of life across four dimensions—oral symptoms, functional limitations, emotional state, and social condition—revealed an overall positive outlook. These insights emphasize the importance of tailored interventions and educational efforts aimed at both parents and children to optimize oral health management and enhance the well-being of children living with EB.

This study also suggests several immediate practical applications for improving oral health care in children with EB. These include enhanced training for parents, with dentists and healthcare providers offering regular sessions on effective oral health management techniques and appropriate tools to prevent blisters and complications. Establishing specialized dental care programs that provide regular check-ups, preventive care, and treatment by experienced dentists can substantially improve oral health outcomes. This care may include tooth cleaning, fluoride therapy, and the use of chlorhexidine mouthwash. Providing access to specialized oral hygiene tools, such as soft-bristled toothbrushes, plaque identification tablets, and fluoride mouthwash, can help maintain oral health without causing additional harm. Implementing dietary modifications and offering nutritional guidance can reduce the risk of dental caries by reducing sugary food intake, increasing high-protein and low-sugar foods, and educating parents on the use of sugar-free medications and supplements. Finally, encouraging the use of positive coping mechanisms and providing emotional support to both children and parents can help manage the psychological impact of EB, involving acceptance, affirmations, and active parental participation in emotional coping strategies.

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