

ORIGINAL ARTICLE

SPECIALIZED NURSING TERMINOLOGY FOR THE CARE OF CHILDREN AND ADOLESCENTS WITH EPIDERMOLYSIS BULLOSA*

HIGHLIGHTS

1. Contribute to the effectiveness of child and adolescent care.
2. The standardization of nursing language for practice and research.
3. Collaborates with the progress of the Classification System.
4. ICNP® specialist terminology for people with epidermolysis bullosa.

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ABSTRACT

Objective: To build a specialized nursing terminology for the care of children and adolescents with epidermolysis bullosa. **Method:** Methodological, documentary study, built between the months of January to December 2021, in partnership with the ICNP® Center, in João Pessoa - Brazil. Data were analyzed using the *PorOnto* tool and the following theoretical methodological references: the International Classification for Nursing Practice 2019/2020, and human mapping following ISO/TR 12300:2016 and the term validation method. **Results:** The validation process with judges resulted in 480 terms for children and adolescents with epidermolysis bullosa, which were submitted to mapping, resulting in 207 constant ICNP® terms and 273 non-constant ICNP® terms. **Conclusion:** a higher number of non-constant terms is evidenced, which can be justified by the peculiarity of the disease and specific care with children and adolescents. The construction of terminology strengthens the development of diagnoses, outcomes, and nursing intervention.

DESCRIPTORS: Nursing; Standardized Nursing Terminology; Child; Adolescent; Epidermolysis Bullosa.

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INTRODUCTION

Rare diseases represent a percentage ranging from 6% to 10% of all diseases worldwide, and most of them have epithelial fragility, such as epidermolysis bullosa (EB). Epidermolysis bullosa is a group of genodermatoses associated with skin fragility, which leads to the formation of blisters, erosions, and scars on the skin and mucous membranes in response to minimal mechanical friction¹. The worldwide statistics for epidermolysis bullosa are approximately 11 cases for every million inhabitants; in Brazil alone, there are around 2,300 people registered in the DEBRA (*Dystrophic Epidermolysis Bullosa Research Association of America*) Brazil website².

In 2020, a reclassification of EB types was published, pointing out genetic characteristics associated with clinical and histology³. The challenges of this disease are numerous due to its complexity, specificity of care, and plurality of signs and symptoms⁴. It requires from health professionals, especially nurses, the ability to offer systematic, organized, planned, and specialized care, with an eye toward the wholeness of children and adolescents.

In this perspective, nursing has been developing and strengthening the use of standardized languages to characterize its scope and allow its evolution in the profession and in science. The specialized language itself favors the understanding among nursing professionals, therefore, appropriating it is essential for the development of more accurate care plans directed to the specificities of the assisted population⁵.

Terminology is based on a tripod: terms, concepts and objects, and its priority is to describe the objects precisely⁵⁻⁶. The International Classification for Nursing Practice ICNP[®] is a standardized terminology for nursing practice used by nurses to standardize Nursing Diagnoses, Outcomes, and Interventions, defined as pre-coordinated concepts. These are constructed by combining the terms/concepts present in the axes of the Seven-Axis Model. The 2019/2020 version of the ICNP[®] contains 4,475 terms distributed among 10 organizing concepts, 2,035 Pre-coordinated Concepts (related to nursing diagnoses/outcomes and interventions) and 2,430 Primitive Concepts⁶.

The ICNP[®] allows the construction of specific term banks⁶, which are also presented as clinical or specialist terminology⁷ for a clientele or health issue. One of the purposes of the term bank is the vast identification of specific terms, contributing to the construction of pre-coordinated concepts⁶, enabling nurses to develop effective care directed at specificities, such as children and adolescents with rare diseases. To contribute to the development of the Classification, the ICNP[®] Research and Development Center in Brazil, located in the city of João Pessoa - Paraíba, has been expanding this range through dissertations and thesis.

The literature highlights specialized terminologies already built for the area of child and adolescent health, such as: Mapping of nursing practice terms in the monitoring of child growth and development⁸; Nursing terminology characterizing domestic violence against children and adolescents⁹; and Adolescent health promotion: specialized language terms for nursing practice¹⁰. However, there is a gap in the identification of specific terms for the care of children and adolescents with epidermolysis bullosa, as well as other rare diseases, justifying the present research.

Therefore, the question is: are the terms identified in publications involving epidermolysis bullosa valid to constitute a specialized terminology that leads to the practice of care and the effective record of nursing care to children and adolescents? Thus, the objective of this study was to construct a specialized nursing terminology for the care of children and adolescents with epidermolysis bullosa.

METHOD

Methodological study, of documentary nature, built in the period from January to December 2021, because of one of the stages of the dissertation "Diagnoses, Outcomes, and Nursing Interventions in children and adolescents with epidermolysis bullosa". It followed the Brazilian method of Nóbrega et al¹¹ for the construction of specialized terminology: 1) identification of relevant terms for nursing clinical practice related to the care of children and adolescents with epidermolysis bullosa; 2) mapping of the identified terms with terms from the ICNP[®] version 2019/2020. It also used as theoretical methodological references: the ICNP[®] 2019/2020 and human mapping following ISO/TR 12300:2016¹², and Pasquali's method¹³ for term validation.

The research is linked to the project "ICNP[®] terminological subsets for clinical specialties and primary health care areas - Phase II: Structuring and clinical validation of ICNP[®] terminological subsets" and had the partnership of the ICNP[®] Centre of Brazil, in João Pessoa, considered a reference in research, development and dissemination of the ICNP[®].

All specialists who consented to participate in the study voluntarily signed the Informed Consent Form (ICF), guaranteeing their anonymity and confidentiality. It is worth mentioning that the participants were informed that they could abandon the research at any time.

The following documents were used for the construction of the final research product and the source of data collection: Clinical Protocol and Therapeutic Guidelines to Hereditary and Acquired Epidermolysis Bullosa of the Ministry of Health, version 2020, official documents of the International Epidermolysis Bullosa Research Association (DEBRA) and databases through a systematic review, guided by the following question: what are the terms used in nursing care in the care of children and adolescents with epidermolysis bullosa in the hospitalization period? Soon after, the *PorOnto*¹⁴ tool was used for semi-automatic construction of ontologies in Portuguese, thus making it possible to identify the terms in the first step and then the CVC (Content Validity Coefficient), proposed by Pasquali (2009)¹³ and ISO/TR 12300:2016¹² for the mapping of terms with the ICNP[®], version 2019/2020.

A deep and detailed search was carried out through a systematic review of the literature to identify relevant terms for the care of children and adolescents with epidermolysis bullosa. The initial investigation in the databases totaled 202 articles, and, after meeting the inclusion and exclusion criteria, presented in the study protocol (Figure 1), eight scientific articles and two official documents were part of the final sample.

The scientific articles were grouped in a single Word file, at this point, the text went through a process of removing information with low potential, such as authorship, abstracts, footnotes, method, references, acknowledgements, annexes, and appendix. It was then converted into the Portable Document Format (PDF), called "PDF of the bases". It is emphasized that this conversion is mandatory to run in the *PorOnto* tool. The official documents went through the same process, generating the document "PDF of the documents".

The two PDFs formed the *corpus textual*. Subsequently, the mapping was performed with terms from the ICNP[®] 2019/2020 version. Figure 1 presents the methodological description of the study.

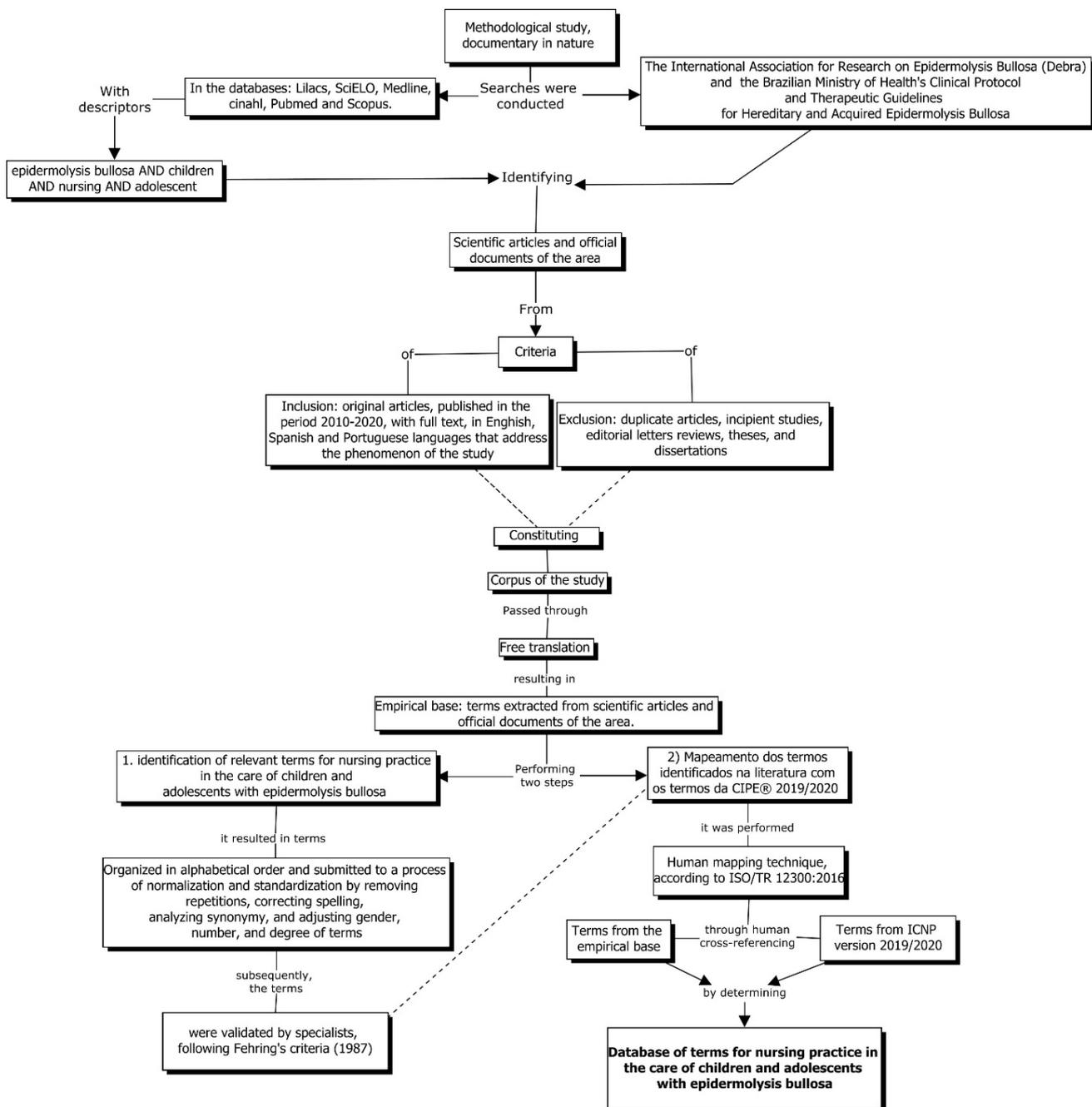


Figure 1 - Conceptual map of the method. João Pessoa, Paraíba, 2022. Note: ICNP®: International Classification for Nursing Practice.

Source: The Authors, 2022.

For the analysis and identification of relevant terms for nursing clinical practice related to the care of children and adolescents with epidermolysis, the *textual corpus* was sent to the *PorOnto* Tool, starting the process of identifying the terms. The tool, in an automated way, processed the two PDFs and extracted the terms, originating an Excel spreadsheet.

The extraction of terms through the analysis to exclude repeated terms and those that were not related to the research resulted in the removal of some terms, such as nouns, verbs, adverbs, verbal locutions, and adverbial locutions. It then went through the process of normalization and standardization with the removal of spelling corrections and the adequacy of gender, number, and degree.

The terms were organized in alphabetical order, in an instrument, and submitted to the process of content validation by a group of judges, so that they could confirm the

relevance of the terms for the nursing care practice in the care of children and adolescents with epidermolysis bullosa. Thirteen instruments were sent, of which six were answered by the experts within 30 days.

As for the specialists, 5 (83%) prevailed in teaching activities. It was registered that most 5 (83%) of the nurse specialists had between 10 and 35 years of training. As for the degree of education, 3 (50%) are PhDs and the other 3 (50%) are masters.

As for the mapping of the terms identified with terms from the ICNP® version 2019/2020, the list of validated terms, after analysis by the experts, was submitted to the human mapping technique according to ISO/TR 12300:2016¹². Human mapping is characterized by mapping in which one starts from the source terms/concepts (validated terms) to the target terms/concepts (ICNP® Seven Axes Model). This type of mapping allows the use of electronic or computational tools to support the researcher. Thus, an Excel spreadsheet was created, containing the validated terms and another with the primitive ICNP® terms.

The spreadsheets were imported into the Access for Windows program for cross-referencing, thus resulting in a table of constant and non-constant ICNP® terms. Next, the non-constant terms went through the equivalence grade process, following the ISO/TR 12300:2016¹² guidelines: grade 1: equivalence of lexical and also conceptual meaning; grade 2: equivalence of meaning, but with synonymy (if the identified term is similar to the ICNP® term); grade 3: the source concept is broader and has less specific meaning than the target concept/term (ICNP®); grade 4: the source concept (identified term) is narrower and has more specific meaning than the target concept/term; and grade 5: no mapping is possible.

It is worth pointing out that when the source term was judged as grade 1 and 2, they were replaced by the equivalent in the ICNP®, thus becoming considered a constant term. The others were maintained as non-constants.

The non-constant terms were classified according to the ICNP® Seven Axes Model, as well as the constant ones, resulting in primitive terms of the specialized nursing terminology for the care of women in situations of obstetric violence, constant and non-constant in the ICNP® 2019/2020 version.

At the end of this analysis, the specialized nursing terminology for the care of children and adolescents with epidermolysis bullosa was constructed.

The research was submitted to the appreciation of the Research Ethics Committee (CEP) of the Health Sciences Center and approved, obtaining registration by CEP: 4.937.784, in accordance with the ethical aspects referenced in Resolution No. 466/2012 and 510/2016 of the National Health Council, which regulates research involving human beings, respecting all ethical and legal precepts.

RESULTS

They were extracted with 4,505 terms from the *PorOnto* ferment, whereby the repetitions were removed, resulting in 1,118 terms. These went through a normalization process, leaving 604 relevant terms. The terms went through the validation process, and this analysis showed a validated rate with $CVC \geq 0.80$ among the participants. The validation process with judges resulted in 480 terms for child and adolescent with EB, of these, 51.66% (312) had $CVC \geq 0.90$ and 27.81% (168) had $CVC \geq 0.80$ and ≤ 0.90 .

The 480 terms were subjected to human mapping, from which resulted 207 constants in ICNP® and 273 not constant in ICNP®. Among the 208 constants, 122 are contained in

the Focus axis, 13 in the Judgment axis, 33 in the Means axis, 14 in the Action axis, six in the Time axis, seven Client axis, and 13 in the Location axis, presented in chart 1.

Chart 1- Examples of terms identified as relevant and classified as constant in ICNP® 2019/2020, João Pessoa, Paraíba, Brazil, 2022

E	Constant Terms
F	Agitation; Adherence; Adherence to dietary regimen; Water; Breastfeeding; Range of Motion; Anxiety; Family support; Aspiration; Self-control; Autonomy; Self-care; Skin self-care; Allergy; Family support; Aspiration; Ability to bathe; Wound healing; Complication; Psychological condition; Confusion; Knowledge; Knowledge of family; Knowledge about disease process; Awareness; Oral (or Oral) condition; Psychological condition; Bowel condition Constipation; Pain control; Guilt; Caring (or Taking Care); Family care; Crying; Shock; Growth; Joint contracture; Dentition; Electrolyte imbalance; Dehydration; Malnutrition; Poor manual dexterity; Difficulty in coping with the disease; Pain; Phantom pain; Wound pain; Muscle pain; Family education; Side effect; Emotion; Negative emotion; Elimination; Coping; Balance; Fluid balance (or fluid balance); Erythema; Heat rash Erythema diaper rash; Tissue erosion; Stress; Exposure to Contagion; Fatigue; Fissure; Wound; Open wound; Epidermal wound; Frustration; Blood glucose; Hyperthermia; Hypothermia; Depressed mood; Social isolation; Infection; Inflammation; Restlessness; Skin integrity; Adverse drug interaction; Injury; Management (control) of disease by oneself; Mucous membrane; Oral mucosa membrane; Fear; Mobility; Non-adherence to dietary regimen; Nausea; Need; Need for care; Necrosis; Obstruction; Odor; Hygiene pattern; Dry skin; Weight; Privacy; Pruritus; Burning; Fall; Anger; Reflex; Motor reflex; Rehabilitation regimen; Resistance; Response to therapy; Respiratory rhythm; Bleeding; Education service (or Education); Sign of infection; Vital sign; Symptom; Symptom of infection; Sleep; Suffering; Suction; Susceptibility; Mortality rate; Scar tissue; Temperature; Trauma; Ulcer; Urine; Imbalanced fluid volume; Vomiting.
J	Delayed (or slow); Complex; Continuous; Effective; Extent; Severity; Improved; Negative; Harmed; Progress; Risk.
M	Water; Needle; Analgesic; Catheter; Wound cover (dressing); Cushioned bed cover; Mattress; Bed; Bath device; Elastic diaper; Supplemental electrolyte; Interprofessional team; Diaper; Gauze; Nutritional intervention; Gloves; Medication; Plan of care; Enteral nutrition regimen; Sedative; Nursing service; Nutrition service; Child health service; Solution; Nutritional supplement; Relaxation technique; Swallowing technique; Therapy; Environmental therapy; Electrolyte therapy; Sensory stimulation therapy; Occupational therapy; Enteral tube; Diaper change.
A	Relieve; Orient; Friction; Control; Wound care; Drain; Educate; Instruct; Immobilize; Monitor; Prescribe; Plan; Suck (or aspirate) airway; Treat.
T	Day; Event or episode; Situation; Chronic; Frequency; Present.
C	Adolescent; Caregiver; Child; Family; Patient; Parent; Newborn
L	School; Hand; Wound Location; Lip; Nipple; Skin; Foot; Tracheostomy; Nail; Intensive Care Unit; Cutaneous route; Ocular route; Topical route.

Note: E: ICNP® Axis; F: Focus; J: Judgement; A: Action; M: Means; T: Time; C: Client; L: Location

Source: The Authors, 2022.

Among the 273 non-constants, 155 are contained in the Focus axis, 28 in the Judgment axis, 72 in the Means axis, four in the Action axis, two in the Time axis, one Client axis, and 11 in the Location axis, presented in table 2.

Chart 2- Examples of terms identified as relevant and classified as non-constant in ICNP® 2019/2020, João Pessoa, Paraíba, Brazil, 2022

E	Non-constant terms
F	Pain relief; Oral feeding; Change; Routine change; Humid environment; Quiet environment; Care improvement; Tissue abnormality; Atrophy; Skin atrophy; Activity; School activities; Aversion; Resistant bacteria; Energy balance; Bath; Bubbles; Bubbles clustered; Simple bubbles; Repeated bubbles; Mucocutaneous blisters; Adherent border; Contact layer; Shear; Eyelid scar; Coagulation; Skin collapse; Bacterial colonization; Expressive behavior; Care; Specific care; Bacterial growth; Crust; Crust loose; Diaper occlusion effect; Antimicrobial effect; Parental effort; Stages of healing; Environmental stimulation; Sensory stimulation; Palate erosions; Exacerbation; Experience; Negative experience; Evidence of pain ; Bowel elimination; Skin involvement; Erosions on the palate; Esophageal erosions; Fragility; Skin detachment; Nutritional deficiency; Iron deficiency; Desquamation; Dislocation of the fingers; Difficulty with swallowing; Dystrophy; Rare disease; Infectious disease; Inherited disease; Photosensitivity; Friction; Fluid from blisters; Hypoplasia; Dental hypoplasia; Hypergranulation; Hyperkeratosis; Hyperkeratosis of the palms; Hypersensitivity; Oral hypersensitivity Immobility; Impossibility of diet Exuberant granulation; Periorificial granulation; Intoxication; Nose irritation; Mobilization; Coagulation necrosis; Loss of hand functionality; Loss of teeth; Loss of electrolyte fluids; Loss of blood; Loss of tissue; Follow-up planning; Poikiloderma; Deprivation; Sleep deprivation; Quality of sleep; Nail drop; Reflux; Therapeutic regimen; Rest; Skin breakdown with trauma; Sedentary; Sensation of control; Sensitivity; Minimal suction; Psychological distress; Body overheating; Tissue; Physical trauma; Psychological trauma; Trauma; Change of dressing; Redness; Vulnerability;
J	Adequate; Altered; Abnormality; Increased; Absent; Low; Complex; Discontinuation; Deterioration; Uncomfortable; Disproportionate; Painful; High; Excessive; Immature; Infected; Ineffective; Ineffective; Unstable; Intense; Soft; Warm; Multiple; Reduced; Loss; Early; On its own; Tranquil.
M	Warm water; Acetic acid; Mepilex® Adhesive; Silicone adhesive; Pharmacological agents; Harmful agent; Calcium alginate; Specialized care; Antimicrobials; Bathing; Bath; Bath with chlorhexidine; Bath with bleach; Bathing tub; Silver salt base; Silicone base; Silicone contact layer; Short bristles; Soft bristles; Gel Mat; Adherent dressing; Non-stick dressing; atraumatic dressing; Biological dressing; Foam dressing; Soft foam dressing; Specific dressing; Adhesive dressing; Advanced dressing; Edge dressing; Chlorhexidine; Sodium chloride; Hydrogen peroxide cream; Bubble fluid drainage; Diaper rash; Dressing choice; Specific emulsion; Sponge; Silicone foams; Silicone foam by mepilex®; Soft foams; Debridement; Keratin gel; Gastrostomy; Vaseline gauze; Kangaroo method; Swallowing skills; Hemostatic moisturizer; Hydrogel; Complex instructions; Cotton gloves; Oxygenation; Tissue oxygenation; Zinc oxide; Zinc oxide paste; Soft paraffin; Muscle relaxation; Adapted shoes; Sedative; Soft silicone; Silicone by mepilex®; Silicone under fixation; Silicone under catheterization; Soft silicone; Sodium in water concentration; Acetic solution; Saline solution; Glucose solution; Saline solution; Iron supplementation; Handling techniques; Topical therapy; Antimicrobial therapy; Emotional treatment; Pharmacological treatment; Symptomatic treatment; Device exchange; Vaseline.
A	Relieve; Pharmacological intervention; Nutritional intervention; Instructions; Clean.
T	Daytime; Cleavage.
C	Multi-professional.
L	Environment; Limited areas; Injured areas; Home; Oropharyngeal; High friction areas; Eyelid eversion; Blister sites; Eyelid; Xerotic skin Granulation tissue; Rough zone.

Note: E: ICNP® Axis; F: Focus; J: Judgement; A: Action; M: Means; T: Time; C: Client; L: Location

Source: The Authors, 2022.

DISCUSSION

The structuring of specialized terminology, characterized by the set of terms, makes the language representative of the phenomenon “epidermolysis bullosa” objective and enhances communication and understanding of the terms for the phenomenon⁵.

As regards the constant terms, in the Axis of Focus, the ICNP® defines this axis as an area of relevant attention for Nursing, among them, "itching", "complication", "care", "skin", "pain", "wound", "wound healing", "sign of infection" stand out.

Itching is a common symptom in all subtypes of epidermolysis bullosa, the urge to scratch is so intense that it can damage intact skin and skin with a healing wound¹⁵. A study conducted in the United States, with 146 patients, showed that itching was the most bothersome complication, its highest occurrence was at bedtime, and among the factors that aggravate this symptom are wound healing, dry skin, infected wounds, stress, heat, dryness, and humidity¹⁶.

Research directly related to skin care in patients with epidermolysis bullosa is scarce¹⁷; nevertheless, it is known that there is a standard which varies among countries and covers skin cleaning, dressing change, and pain control¹⁸. DEBRA Brazil follows a guideline on skin care for epidermolysis bullosa¹⁹.

Although each country has guidelines to follow, there is a significant rate of skin infections. A study conducted in a reference hospital in Rome revealed that 87% of 108 patients with dystrophic epidermolysis bullosa had skin infections. The most recurrent complication in patients with EB is sepsis, considered the main cause of morbidity and mortality in children and adolescents, but in adolescents and adults it is carcinoma²⁰.

The nurse needs to be aware of the signs of infection to intervene in a timely manner and treatment. Wound care, besides being in accordance with the treatment centers, should include the topical application of an emollient cream on the whole skin, whether it has a wound or not, especially if the patient requires frequent dressing changes. This strategy stimulates epidermal barrier repair, reduces itching, minimizes trauma to existing wounds, and protects intact skin¹⁸.

Intervention measures for the skin and wounds are necessary because chronic wounds excessively stimulate inflammation, fibrosis, and tumor progression, and infected wounds increase the risk of developing sepsis²⁰. Open wounds are mostly colonized by resistant bacteria, most commonly methicillin-resistant *Staphylococcus aureus* (MRSA), *Pseudomonas aeruginosa*, and *Streptococcus*²¹.

Wounds and itching impact mental health and well-being, predisposing to deficit in functional capacity and socialization with others²². Psychosocial disorders, such as anxiety, stress, depressed mood, social isolation, constant terms in the ICNP®, predispose to complications and increased pain²¹. However, in an investigation on anxiety, depression, and self-esteem, carried out in Mexico, with 27 patients with the disease, it was pointed out that pain is not related to anxiety and depression²³.

Regarding the axis Judgement, the ICNP® defines clinical opinion as the focus of nursing. More negative judgments are observed because it is a disease of difficult diagnosis, prognosis and treatment⁴.

In the Means axis, terms such as "needle" and "wound covering" are contained. The needle can be a means to burst the blisters, in this circumstance, it is paramount to know the correct technique to avoid further pain and harm to children and adolescents²⁴.

The appropriate wound cover depends on the subtype of EB, the characteristics and location of the wound. Dressings are always innovating to serve the patient and bring less pain, a study in London presented a type of dressing in the form of a dressing glove for patients with recessive dystrophic epidermolysis bullosa, and the reduction of pain was observed²⁵.

Research conducted in a reference hospital for dermatological diseases in Indonesia, investigated wound dressings, whose results indicated that both the biocellulose and the carbocoxymethyl cellulose dressings significantly reduced the areas of the wounds and

their complete healing time when compared to dressings with normal saline solution on skin wounds, indicating that both are equally satisfactory for treating wounds in children and adolescents with EB²⁶.

With the objective of improving more and more the quality of life of these patients, researchers in the area investigate and present innovations on the subject; therefore, it is necessary that nurses use research to apply it in practice, since they are evidence-based practices.

To bring positive results, nurses are required to know the physio pathology and its clinical manifestations, to know the patient's psychological and social status, and to listen to the patient's wishes. These interventions are represented by actions such as: relieve, orient, rub, drain the blister, educate, instruct, monitor, suck (or aspirate) airways, and treat, terms contained in the Action Axis. In a case study carried out with a newborn affected by the disease, when these actions were implemented, significant improvements were observed in the child²⁷.

In the Time axis, among the constants, the term Chronic is intensely associated with epidermolysis bullosa, considering that it is a disease with no cure, of chronic condition¹, generally, with chronic wounds, chronic inflammation, and many times, patients present chronic pain²⁰.

In the Client, "Child" and "Adolescent" are the individuals most affected by the disease; it is in this age group that many stigmas and prejudices start to appear, and even progress, affecting the biopsychosocial development. The term Caregiver refers to those who care directly or indirectly; they often suffer the impact of interpersonal, parental, emotional, and financial relationships, in addition to constant worries and sacrifices. The arrival of a newborn with epidermolysis bullosa is a challenge for the whole family, which often needs psychological support from health professionals²⁸.

Finally, related to the constant terms, in the Location axis, the term "Skin" stands out. Epidermolysis bullosa is a rare dermatological disease that affects the skin, making it fragile due to dysfunction between the dermis and epidermis, causing flaking and erosive disorders, such as blisters and wounds. Epidermal wounds, a Focus axis term, can involve all layers of the skin, epidermis, appendages, dermis, and subcutaneous²⁹.

As for the non-constant terms, these are terms that are not included in the ICNP[®] and are generally more specific to the health problem and the clientele studied. There is a higher number in the Focus axis, followed by the Means axis, in which more specific EB terms are observed.

In the Focus axis, the term "Blisters" is a central point for nurses assisting patients with epidermolysis bullosa. They usually appear as grouped blisters, simple blisters, repeated blisters, mucocutaneous blisters, and appear, spontaneously, at the slightest friction with the skin, by friction of a dressing, tight clothes, socks, shoes, or boots, and by touch with inadequate pressure. Thus, increasing susceptibility to the risk of infection³⁰.

The blisters, wounds, or other clinical manifestations of EB are judged clinically by nurses and patients as "Painful", "Infected" and "Multiple", "Excessive". Such terms, despite their inconstancy in ICNP[®], are very recurrent in nurses' judgment²⁹.

To intervene in the progression to complications, together, the Ministry of Health and the Brazilian Dermatological Association, in 2021, elaborated a protocol of non-pharmacological guidelines for the multi-professional team, in terms of the Client axis. Among the guidelines, the following stand out when removing the dressing, whether biological, adherent, or adhesive, one should irrigate with 0.9% sodium chloride solution; if there is a large, affected body surface or with infected lesions, according to the recommendations established by the PICS (Integrative and Complementary Health Practices), it is not recommended to take a bath as a relaxation technique and to improve

quality of life³⁰.

The terms “biological or adherent or adhesive dressing”, “sodium chloride”, “immersion bath”, “relaxation technique” are in the axis - Means - and, although not included in the ICNP®, are significant and relevant terms for the care of children and adolescents with epidermolysis bullosa.

In the axis Action, the non-constant term “Clean” refers to cleaning the wound, cleaning the wound bed, and wound surrounding area. Attention should be paid, when cleaning the diaper area, to avoid sanitary towels and to be careful when cleaning high friction areas²⁹⁻³⁰, a non-constant term from the Location axis.

The Time axis term, - Cleavage - refers to an important period to classify the epidermolysis bullosa, for this, it will depend on the cleavage level of the skin in the epidermal keratinocyte or in the basement membrane area. There is a microscopic technique that observes this level of skin cleavage in the keratinocyte, facilitating the diagnosis of EB and its possible classification²⁸⁻³⁰.

Finally, by discussing relevant terms for the care of children and adolescents with epidermolysis bullosa, it is evident that significant contributions were brought, such as improvement of care due to the expansion of knowledge, stimulus for a more assertive clinical and critical reasoning, favoring of precision in decision-making, and ability to promote health promotion, prevention, recovery, and rehabilitation.

As a limitation of the study, we highlight the use of articles, mostly in English, which needed to undergo a process of translation into Portuguese, and thus, there may have been a loss of some evidence and damage in the development of the bank of terms of the study. We also point out the difficulty in returning the validation instruments.

CONCLUSION

The objective of the study was met as it allowed the construction of a specialized nursing terminology for the care of children and adolescents with epidermolysis bullosa, with 480 validated terms, of which 207 (43.13%) were constant in the ICNP® and 273 (56.87%) were not constant in the ICNP®. There was a higher number of terms that were not constant, especially in the Focus axis with 155 terms and the Means axis with 72 terms. This may be justified by the peculiarity of the disease and the specific care that children and adolescents require.

With this research, it is expected that the specialized terminology will help nurses in the nursing process, allowing the construction, based on the ICNP®, of diagnoses, outcomes, and nursing interventions for the patient-family binomial.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Araujo BGS de, Beserra PJF, Silva K de L.** Drafting the work or revising it critically for important intellectual content - **Araujo BGS de, Dantas AMN, Silva K de L.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Araujo BGS de, Beserra PJF, Silva K de L.** All authors approved the final version of the text.

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