Revista Brasileira de Enfermagem
REBEn

THEMATIC EDITION
ADVANCED NURSING PRACTICES

ORIGINAL ARTICLE

Development and validation of educational hypermedia for family members and caregivers of people with epidermolysis bullosa

Desenvolvimento e validação de hipermídia educativa para familiares e cuidadores de pessoas com epidermólise bolhosa

Desarrollo y validación de hipermedia educativa para familiares y cuidadores de personas con epidermólisis ampollosa

Paulo Sérgio Dionísio[I]
ORCID: 0000-0003-3196-2029

Islene Victor Barbosa[I]
ORCID: 0000-0003-3523-7238

Luís Rafael Leite Sampaio[II]
ORCID: 0000-0003-1437-9421

Karla Maria Carneiro Rolim[I]
ORCID: 0000-0002-7914-6939

Silvia Karina Moreira Seifert[III]
ORCID: 0000-0002-5058-9963

Gleison Resende Sousa[I]
ORCID: 0000-0001-5805-9281

Rita Neuma Dantas Cavalcante de Abreu[I]
ORCID: 0000-0002-5130-0703

Elizete Rios de Vasconcelos[I]
ORCID: 0000-0002-9823-2269

[I]*Universidade de Fortaleza. Fortaleza, Ceará, Brazil.*
[II]*Universidade Regional do Cariri. Cariri, Ceará, Brazil.*
[III]*Pontifícia Universidade Católica. Curitiba, Paraná, Brazil.*

How to cite this article:
Dionísio PS, Barbosa IV, Sampaio LRL, Rolim KMC, Seifert SKM, Sousa GR, et al. Development and validation of educational hypermedia for family members and caregivers of people with epidermolysis bullosa. Rev Bras Enferm. 2022;75(5):e20210856. https://doi.org/10.1590/0034-7167-2021-0856

Corresponding author:
Paulo Sérgio Dionísio
E-mail: pdio2007@hotmail.com

EDITOR IN CHIEF: Antonio José de Almeida Filho
ASSOCIATE EDITOR: Hugo Fernandes

Submission: 11-17-2021 **Approval:** 04-22-2022

ABSTRACT

Objectives: to develop educational hypermedia to support the care of people with epidermolysis bullosa; and validate its content, functionality, usability, and efficiency. **Methods:** methodological study, based on five phases: analysis and planning; modeling; implementation; evaluation; and distribution. Hypermedia was evaluated by expert judges, using the content validity index, index of agreement, and exact binomial distribution test, considering $p > 0.05$ and 0.80 agreement ratio to estimate the statistical reliability of CVI and IOA. **Results:** in the validation with the judges, hypermedia presented excellent indices of total content validity (CVIt=0.99) and agreement for functionality, usability, and efficiency (IOA=100%), with $p > 0.05$ in all evaluated items. **Conclusions:** the developed hypermedia was considered adequate, with good screens, descriptions, and animations, presenting itself clearly and objectively to be used by patients with epidermolysis bullosa and their family members/caregivers.
Descriptors: Epidermolysis Bullosa; Caregivers; Educational Technology; Hypermedia; Validation Study.

RESUMO

Objetivos: desenvolver uma hipermídia educativa para fundamentar os cuidados à pessoa com Epidermólise Bolhosa, e validar seu conteúdo, funcionalidade, usabilidade e eficiência. **Método:** estudo metodológico, fundamentado em cinco fases: Análise e planejamento; Modelagem; Implementação; Avaliação e Distribuição. A hipermídia foi avaliada por juízes especialistas, por meio dos testes de Índice de Validade de conteúdo, Índice de Concordância e Exato de Distribuição Binomial, considerando p>0,05 e proporção de 0,80 de concordância para estimar a confiabilidade estatística dos IVC e IC. **Resultados:** na validação com os juízes, a hipermídia apresentou excelentes índices de validade de conteúdo total (IVCt=0,99) e concordância para funcionalidade, usabilidade e eficiência (IC=100%), com p>0,05 em todos os itens avaliados. **Conclusões:** a hipermídia desenvolvida foi considerada adequada, com boas telas, descrições e animações, apresentando-se de forma clara e objetiva para ser utilizada pelos pacientes com epidermólise bolhosa e seus familiares/cuidadores.
Descritores: Epidermólise Bolhosa; Cuidadores; Tecnologia Educacional; Hipermídia; Estudos de Validação.

RESUMEN

Objetivo: desarrollar una hipermedia educativa para fundamentar los cuidados a la persona con epidermólisis ampollosa; y validar su contenido, funcionalidad, usabilidad y eficiencia. **Métodos:** estudio metodológico, fundamentado en cinco fases: Análisis y planeamiento; Modelado; Implementación; Evaluación; y Distribución. La hipermedia fue evaluada por jueces especialistas, mediante los testes de índice de validez de contenido, índice de concordancia y test exacto de distribución binomial, considerando $p > 0,05$ y proporción de 0,80 de concordancia para estimar la confiabilidad estadística del IVC e IC. **Resultados:** en la validación con los jueces, la hipermedia presentó excelentes índices de validez de contenido total (IVCt=0,99) y concordancia para funcionalidad, usabilidad y eficiencia (IC=100%), con $p > 0,05$ en todos los ítems evaluados. **Conclusiones:** la hipermedia desarrollada fue considerada adecuada, con buenas pantallas, descripciones y animaciones, presentándose de manera clara y objetiva para ser utilizada por los pacientes con epidermólisis ampollosa y sus familiares/cuidadores.
Descriptores: Epidermólisis Ampollosa; Cuidadores; Tecnología Educacional; Hipermedia; Estudios de Validación.

ONLINE VERSION ISSN: 1984-0446

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INTRODUCTION

Epidermolysis bullosa (EB) is a group of rare genetic skin diseases, of hereditary character, caused by several mutations in structural proteins responsible for intraepidermal and dermoepidermal adhesion of the skin. It causes the appearance of blisters in the cutaneomucosal region of the body in response to minimal trauma, heat, or spontaneously, which can manifest themselves at birth or during the first years of life[1].

In Europe, the prevalence of EB is 1.9/100 thousand among those born. In Brazil, studies are scarce and usually consist of small samples or case reports, mainly addressing clinical data[2]. There are 994 individuals registered with EB currently in the country and, 147 of these have evolved to death so far. Of the total registered, there are 406 living people aged between 0 and 15 years[3].

As the society knows little about this rare disease, most health professionals also have limited clinical knowledge about it, which harms the diagnosis, treatment process, and, especially, support measures for patients and their families/caregivers, implying greater complexity in the essential care for people with EB[4]. In addition, it is necessary to insert scientific robustness regarding the treatment of patients with EB through the expansion of a health education process. It is because most professionals may have deficient knowledge regarding therapeutic decision-making and measures to support the family/caregiver binomial.

The expansion of health education using information and communication technologies (ICTs) has provided a breakdown of cultural and geographical barriers, with the ability to cover everyone and thus ensure compliance with the principle of universality[5]. Therefore, the development of an educational ICT of the hypermedia type, based on the knowledge and needs of nurses and the family/caregiver binomial and subsidized by evidence, is a technological innovation to be incorporated into the nursing care practice for the care of the person with EB, aiming to provide better care and quality of life.

The development of hypermedia is justified by the complexity of this disease, the difficulty for nurses to obtain technical and scientific knowledge, which can generate fragility in nursing care, and the absence of a specialized support network to support the treatment process. In addition, there is a lack of mobile applications for the disease available in the scientific literature and virtual stores.

OBJECTIVES

To develop educational hypermedia to support the care of people with epidermolysis bullosa; and validate its content, functionality, usability, and efficiency.

METHODS

Ethical aspects

This study was approved by the Research Ethics Committee (CEP) of the University of Fortaleza (UNIFOR), as established by Resolution No. 466/12 of the National Health Council.

Design, period, and place of study

A methodological study, based on the precepts advocated by Falkembach[6], which describes the development of digital material in five phases: 1) Analysis and Planning (definition of the theme, objective, and target audience); 2) Modeling (construction of the models); 3) Implementation; 4) Evaluation; and 5) Distribution. The study followed the guidelines of the SQUIRE 2.0 instrument (equator network) to guide the methodology.

This study was conducted from January 2020 to February 2021 in a State pediatric institution of public character, reference in the care of children with EB, located in a city in northeastern Brazil.

Population or sample; criteria of inclusion and exclusion

The study had the participation of three samples: caregivers, nurses, and computer technicians.

Six family members/caregivers of people diagnosed with EB of both sexes, treated at the institution's specialized wound care service, were selected. Sample selection was for convenience. The invitation for family members to participate in the research was made through a notice posted on the door of the consultation clinic.

The selection criteria established were: people aged 18 years or more who lived with people with EB, who were registered at the institution of the study and/or at the State Department of the Health of Ceará (SESA) in the full domain of consciousness and who agreed to participate in the study by signing the Informed Consent Form (ICF). The study excluded family members/caregivers of the person with EB who was terminally ill, respecting the delicate state in question.

In the validation phase of content, appearance, functionality, usability, and efficiency, the study selected the judges by searching the Lattes platform and appointing experts from the researchers' relational universe ("snowball" technique). The judges were nurses, with post-graduation in Stomatherapy and or with experience of at least one year in the care of people with EB. The judges for the technical validation of the Informatics area had higher education in Computer Science and/or System Analysis and/or Digital Media. The exclusion criteria adopted were the absence of return of the evaluation and/or the lack of communication with the researcher for more than 20 days.

Study protocol

Phase I defined the theme and objectives of hypermedia. Thus, the theme chosen to be addressed by hypermedia was EB to scientifically substantiate the care of people with this pathology and subsidize/empower family members/caregivers through validated content. Also in this phase, an integrative literature review was conducted to investigate essential care, focusing on the quality of life of people with EB; and the survey of the demands of family members and caregivers through interviews.

In the review, the study applied the PICo strategy to construct the question: What is the relevant evidence that supports nursing care for people with EB in the home context? The data were collected in the electronic databases: Latin American and Caribbean Literature in Health Sciences (LILACS), PMC (PubMed

Central), and Cumulative Index to Nursing and Allied Health Literature (CINAHL) between August and October 2020. Access was through the Portal of Periodicals of the Coordination for the Improvement of Higher Education Personnel; and the descriptors were selected after consulting the vocabularies Medical Subject Headings (MeSH), Health Science Descriptors (Decs), and CINAHL titles.

The inclusion criteria delimited for the pre-selection of the studies were: articles that contemplated the proposed objective; indexed in the aforementioned databases; timeless; in English, Portuguese, or Spanish languages; and available electronically in full. It excluded editorials, letters to the editor, works published in events annals, and thought-provoking articles.

Also, a bibliographic survey was conducted of uncontrolled search in national and international bodies related to the health of the person with EB: Ministry of Health; Brazilian Society of Pediatrics (SBP); Brazilian Society of Dermatology (SBD); International Association of Dystrophic Bullous Epidermolysis (Adebra International); Brazilian Association of Dystrophic Bullous Epidermolysis – Brazil (ADEBRA-BR); revised consensus. The survey also considered the content extracted and analyzed from the interviews conducted by the subjects of this research.

Then, a semi-structured interview was conducted, at previously agreed times and days, to understand the perception of family members and caregivers about care for EB. The interviews had two questions: "For you, family members/caregivers, what is it like to take care of the person with EB in your home"; "What were the guidelines you received at hospital discharge regarding bathing, feeding, clothing, and skincare (injury prevention and treatment)"? The answers were recorded and transcribed, and the data obtained were used only for this study, which will be stored by the researcher for up to five years, after which they will be destroyed. The confidentiality and anonymity of the interviewees were observed, according to the precepts of the legislation that regulates this study.

After reading the scientific material from the review and analysis of the discourses, Phase 2 was followed, with the construction of the models (low-quality prototyping). Phase 3 was characterized by the production, digitization, and creation of the project's media, including sounds, images, animations, and videos, using specific software considering copyright. The construction was conducted by a graphic designer, an illustrator, and a computer engineer and programmer.

In Phase 4, seventeen judges from the nursing area and ten from the Computer Science validated the hypermedia regarding content, appearance, and technical aspects (functionality, usability, and efficiency). A letter of invitation was sent by email to the two groups of judges to participate in the validation process. To those who agreed to participate, the ICF and evaluation instruments were made available through the Google Docs platform.

The nursing judges evaluated the hypermedia regarding the objective; content (structure and presentation strategies); relevance; and environment (the scenario in which the elaborated instrument will be presented). The judges of Computer Science (technicians) evaluated: functionality, usability, and efficiency. Also, the experts suggested improvements for the hypermedia.

Phase 5 defined the execution module, installation roadmap, and the network that would host the hypermedia technology. The team of the Applied Graduate Laboratory (PPGA/UNIFOR) in alignment with the researcher defined this phase.

Analysis of results and statistics

The judges were characterized regarding social and professional data, using descriptive statistics. For numerical variables, the study considered measures of central tendency and dispersion, while the categorical variables were expressed in absolute and relative frequencies.

In the validation analysis process, the content validity index (CVI) was calculated by the average of the responses with grades "3" and "4" given by the judges. The study considered excellent the CVI of the items (CVIi) 0.78 and CVI total of 0.90[7]. The same parameters were used to calculate the index of agreement (IOA) among computer specialists. Also, the exact binomial distribution test was performed, indicated for small samples, being considered a level of significance $p > 0.05$ and 0.80 agreement ratio to estimate the statistical reliability of CVI and IOA.

RESULTS

The integrative review and analysis of the discourses of family members and caregivers made it possible to select the contents and functionalities of hypermedia, called "Flor Da Pele." Thus, they were organized into modules involving the themes: welcome (presentation of hypermedia with information on the objectives and content); understanding EB (skin characteristics, what is the disease, etiology, diagnostics, classification, and treatment), and essential care (care for the newborn, breastfeeding, bathing, prevention and treatment of injuries, clothing, and foot care, feeding, and tooth care). The study opted for the use of animations and images, essential resources for presenting the content to the user (Figure 1).

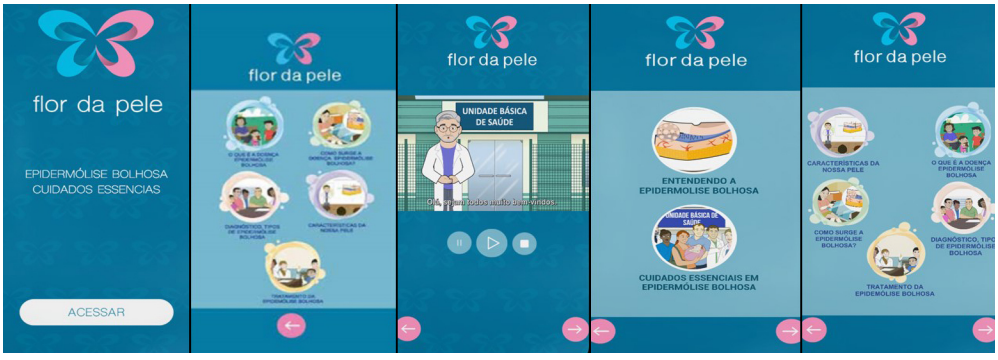

Figure 1 - Hypermedia Interface "Flor da Pele"

Table 1 - Validation of the application content by nurse judges, Fortaleza, Ceará, Brazil, 2021

Item	Agreed		CVI (%)	*p*
	Partially *f*(%)	Totally *f*(%)		
Objectives			1.00	
1 – Are consistent with the practice of caring for people with EB.	1 (5.9)	16 (94.1)	1.00	0.118
2 – Are consistent with the content presented.	3 (17.6)	14 (82.4)	1.00	0.549
3 – Are suitable to be effective.	3 (17.6)	14 (82.4)	1.00	0.549
4 – Are suitable for the teaching and learning process.	3 (17.6)	14 (82.4)	1.00	0.549
Content			0.98	
5 – The content accurately reaches the approach of the topic.	4 (23.5)	13 (76.5)	1.00	0.451
6 – It is suitable for the family/caregiver of people with EB.	5 (29.4)	12 (70.6)	1.00	0.242
7 – The information is current and true.	2 (11.8)	15 (88.2)	1.00	0.310
8 – The information is enlightening and necessary.	1 (5.9)	16 (94.1)	1.00	0.118
9 – The language is suitable for the target population.	4 (23.5)	11 (64.7)	0.94	0.118
Relevance			1.00	
10 – The items illustrate important aspects for essential care for people with EB.	2 (11.8)	15 (88.2)	1.00	0.310
11 – The educational material is relevant and stimulates learning.	2 (11.8)	15 (88.2)	1.00	0.310
12 – It is consistent for the practice of care for people with EB.	-	17 (100.0)	1.00	0.310
Environment			1.00	
13 – Hypermedia is suitable for content presentation.	5 (29.4)	12 (70.6)	1.00	0.242
14 – The resources are suitable for learning the subject.	5 (29.4)	12 (70.6)	1.00	0.242
15 – Resources propose attractive learning situations.	5 (29.4)	12 (70.6)	1.00	0.242
CVIt	-	-	0.99	-

f – absolute frequency; % – percentage; IVC – content validity index; p – binomial test (comparison between answers totally agree/agree and partially disagree).

Chart 1 - Suggestions from judges for content for hypermedia

Judge	Suggestions
J1	Add care for non-care professionals (informal). Add an Afro-descendant oriented professional.
J3	I suggest spelling and grammatical revision. On page 11 – include guidelines regarding bathing. On page 13 – specify whether the care about the bath is for children.
J4	In the first paragraph, in the definition of EB – replace "being able" (gerund) with "and may". Insert pictures on how to put the baby diaper. Unify Topics 4 and 5 in the care in the bath section. Clarify whether the care in the bath is for children or adults.
J9	Expand the use of technology. Re-evaluate the use of some terms, making them clearer to the user.
J10	Bring scientific terms closer to their definition. Include the term "self-care"
J12	Reread to delete repetitive information. Beware of using terms inappropriate to the public.
J14	Evaluate the possibility of transforming the *app* in other educational technology.
J16	Available in Unified Health System (SUS). Put more humor in the photograph. Insert musical background.
J17	Use more illustrations, especially in the description of each care to be provided. Modify scientific terms that may hinder the understanding of users, especially in Figures 5 and 8. Reevaluate the illustrations – some do not match the purpose for which they are set.

In the validation phase, the judges for contents were predominantly female (16; 94.1%), with a median age of 40 years. The average time since training was 19.1 years (SD = 8.5); all had specialization, 13 (76.5%) were masters, 5 (29.4%) were doctors, and 14 (82.4%) participated in research groups. The research also found that 16 (94.1%) had articles published in journals, and 13 (76.5%) reported having experience in teaching. Regarding professional data, the judges were mostly assisting workers (8; 47.1%), working in high complexity units (13; 76.5%), with average care experience of 14.8 years (SD = 9.8).

In content validation (Table 1), the objective, relevance, and environment domains presented CVI equal to 1.00; and the content, CVI equal to 0.98. Only one judge found that the app did not have a language suitable for the target population (item 9, CVI = 0.94). In the binomial test, all items presented $p > 0.05$, indicating the agreement of the score between the judges.

Among the main suggestions, the study observed the judges' concern with the use of scientific terms, which may hinder the understanding of information by the target audience; and with the adaptation and transformation of the application in other technologies, such as a booklet, to expand access (Chart 1).

In the characterization of the computer judges, all were male, with a mean age of 34.9 years (SD = 5.1). They had a graduation time of ten years (SD = 7.3); four (40%) were specialists, five

(50%) were masters, and four (40%) were doctors; seven (70%) said they had experience in teaching. As for professional data, the current occupation and activity were very varied. Three (30%) were teachers. In the field of activity, two (20%) were from information technology.

In the analysis of functionality, usability, and efficiency (Table 2), all items were scored with values corresponding to "partially agree" and "totally agree," with 100% IOA among the judges ($p > 0.05$).

Judges considered the technology adequate, with good screens, descriptions, and animations, presenting itself clearly and objectively. A judge warned concerning animations that only use children or babies at the time of care as the information also covers adults. In addition, the judges suggested the insertion of search resources, patient information, chat, and interaction system with public services. JTI4 added the importance of making the app available on iOS and Android platforms to extend its reach. JTI7 suggested that the application provide opportunities for continuity of care through communication between patient and professional (Chart 2).

In the end, the validation of the educational hypermedia "Flor da Pele - Epidermolysis Bullosa: Essential Care" was obtained. It was considered valid in terms of content, appearance, functionality, usability, and efficiency.

DISCUSSION

The constructed hypermedia aimed to increase the level of knowledge of patients with EB and their relatives/caregivers, mainly concerning the prevention and management of wounds. To that end, it incorporated several functional features, with a predominance of videos. The content was considered relevant, with objective language; and the use of videos facilitated the understanding of the idea to be transmitted.

Educating the person with EB and their family members/caregivers is relevant for disease monitoring. Still, the legitimacy of care should not be forgotten. This action should be continuously stimulated so that caregivers can be guided and provide the user with a life close to the daily routine according to age. There is, in this sense, fragility in the knowledge of both the caregiver and the professional who performs care for the complications of the disease since the references with a level of confidence and strength of recommendation relate to International studies, which do not reflect the reality of Brazil[8].

In the health education process, nurses can rely on actions or information resources and may involve materials designed to facilitate communication and understanding of participants. Health and nursing technologies have evident advances in care,

Table 2 - Validation of functionality, usability, and efficiency by computer judges

	Agreed		CVI (%)	*p*
	Partially *f*(%)	Totally *f*(%)		
Feature				
1 – Hypermedia is presented as an appropriate tool to the proposal for which it is intended.	2 (20.0)	8 (80.0)	100.0	0.302
2 – Hypermedia makes it possible to generate positive results.	1 (10.0)	9 (90.0)		0.107
Usability				
3 – Hypermedia is easy to use.	1 (10.0)	9 (90.0)	100.0	0.107
4 – It is easy to learn the concepts used and their applications.	1 (10.0)	9 (90.0)		0.107
5 – Allows control of the activities presented in it, being easy to apply.	4 (40.0)	6 (60.0)		0.624
6 – Allows the user to have ease in applying worked concepts.	1 (10.0)	9 (90.0)		0.107
7 – Provides help clearly.	2 (20.0)	8 (80.0)		0.302
8 – Provides help in a complete way.	2 (20.0)	8 (80.0)		0.302
9 – Provides help quickly, not being tiring.	3 (30.0)	7 (70.0)		0.624
Efficiency				
10 – Hypermedia design is suitable for your upgrade.	2 (20.0)	8 (80.0)	100.0	0.302
11 – The number of modules is consistent with the proposed time.	-	10 (100.0)		0.107
12 – The organization of thematic topics is suitable for a good understanding of the content, with easy localization of the desired topic.	1 (10.0)	9 (90.0)		0.624
13 – Resources are used appropriately.	-	10 (100.0)		0.107
14 – Resources are used efficiently and comprehensively.	-	10 (100.0)		0.107
IOAt			100.0	

f – absolute frequency; % – percentage; IOAd – domain's index of agreement; p – binomial test (comparison of categories 1 and 2); IOAt – total of index of agreement.

Chart 2 - Suggestions from computer judges for the app

Judge	Suggestions
JTI2	Insert function to fill in concrete and updated user data, such as telephone number/email.
JTI4	Available on iOS and Android platforms.
JTI7	Enter a chat so that users can exchange ideas with each other. Enable follow-up with health professionals.
JTI8	Insert animations closer to the reality of the anomalies caused on the skin.
JTI9	Enter a system of interaction with some public service.
JTI10	Enter a specific information search system. Check that animations involve all age groups.

aiming at the direct improvement of the provision of care to patients and their families. Thus, they can be valuable, among other purposes, to facilitate understanding of certain events and more quickly promote changes for patients[9].

As strategies for health education, mobile health or mHealth, which is based on medical or public health practice mediated by mobile devices such as mobile phones[10], has been used in various health contexts. It also allows the incorporation of educational videos, a resource that provides knowledge and favors critical awareness and health promotion. Educational videos have been used in several pedagogical experiences, demonstrating the relevance of their applicability in the teaching-learning process as they combine several elements, such as images, text, and sound in a single object of knowledge promotion[5].

Good educational material explores not only the cognitive side but also the affective side and uses specific motivation strategies[11]. An effective way to work affectivity is through interface agents, that is, virtual characters capable of perceiving the user's affective states and correctly reacting to them. Interaction with static and animated characters can affect students' learning since the presence of the human figure has a positive effect on students' interactive experiences, showing that they considered a topic under study less complex and the presentation more playful in the presence of a virtual character[12]. To that end, it is essential to incorporate elements that work with aesthetics and affectivity in the interfaces.

Developing an educational material that is attractive, motivating, and contributing to knowledge, (self)care, and decision-making in health is essential for people with EB and their family members/caregivers. In this context, the importance of following theoretical and methodological steps for this development is evidenced. That said, in the present work, expert judges of the area of EB and technology and education were selected to deliver work with correct and relevant information and visually attractive to develop the critical sense[13].

The process of validating educational material is essential to have a reliable technology that gives value to a construct. The creation and validation of technologies are fundamental and complex steps that require pedagogical attitudes and appropriate methods. Without the validation process, there is a risk of making inappropriate material without educational purpose[14]. Also, validating the product by judges and making it available in different mobile operating systems and with a free download makes it possible to obtain better market positioning and competitive advantage, increasing the number of users and, consequently, the diffusion and usability of the app, as well as favoring behavior change[10].

Aiming at the quality and improvement of hypermedia, seventeen nurses and ten IT professionals evaluated it. In general, hypermedia was considered interactive, objective, explanatory, with excellent images and consistent with the content, extremely relevant to the audience to which it is intended. Only one judge said the videos did not have appropriate language. Considering that factors such as schooling and functional literacy in health influence the understanding of information about a health condition[15], there was great concern with the organization of data and choice of terms used in hypermedia.

It is important to emphasize that because it is a rare disease, with low incidence and with a restricted population, there is misinformation in some aspects of the health-disease context on the part of health professionals, which reflects the insecurity of transmitting relevant information about the care of people with EB to family members/caregivers.

Concerning functionality, usability, and efficiency, these requirements help verify that the app makes it easier for users to achieve their goals and see if the incidence of errors is acceptable and how they can be faced. In the teaching-learning process, the functionality of the interface refers to the clarity of the links, ease of displacement between the screens, ease of finding the information, and proper presentation of the contents, without errors and problems[16].

Finally, it is necessary to implement a consistent support network, in which all parts involved in care feel welcomed. In addition, patients and family members/caregivers should deepen their knowledge to promote care based on the best clinical evidence and thus improve their quality of life. In this scope, developed hypermedia can be a motivation for the discussion and implementation of care.

Study limitations

The limitation of this study is the small number of samples of the target population as it is a rare disease with an extremely low incidence and is little known in contemporary times. Another limitation evidenced was the scarce scientific production on the part of Nursing and, which is limited to non-analytical studies based on expert opinions (in the case of consensus).

Contributions to the fields of Nursing and Health

Developed hypermedia is an innovative technology with current and relevant content for the education and care of people with EB. It may be the key to discussing the best evidence and best general care for patients with EB and to minimizing public spending in the short, medium, and long term since the user himself and his family members can access hypermedia remotely, that is, without the need to leave home.

CONCLUSIONS

This study of the construction and validation of educational technology achieved the proposed objectives. The "Flor Da Pele" hypermedia underwent a rigorous process of elaboration of material and evaluation by judges of Nursing and Computer Science, which resulted in a dependable, dynamic, and timeless means of health education regarding the essential care for the person with EB, for use by family members/caregivers and scientific society.

The study designed the information considered relevant to use theoretical content with a simple and objective language, employing various media (images, audios, and animations), which were carefully planned to clarify and complement the idea transmitted, facilitating visual communication, and understanding of the target audience.

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