Creation and validation of a health guidance booklet for family members of children with sickle cell disease

Elaboração e validação de caderneta de orientação em saúde para familiares de crianças com doença falciforme

Elaboración y validación de libreta de orientación en salud para familiares de niños con enfermedad falciforme

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ABSTRACT

The aim of this study was to elaborate a booklet for health follow-up and guidance on sickle cell disease for relatives of children with this disease and validate it. It is a methodological study, conducted from May 2017 to February 2018, of the elaboration and validation of an educational technology, constructed from previous field research in a pediatric hospital in Ceará (ethical opinion nº 994.879 and nº 955.727). Validation of content and appearance occurred by specialized, technical and communication judges; after the adjustments, the evaluation by representatives of the target public took place. The analysis was through the Concordance Index. Results: the evaluation of technical judges and experts reached a Global Concordance Index of 0.93, characterizing the book as good quality. The judges of communication evaluated all items as Superior. As for family members, everyone agreed that the book was adequate. It is concluded that the booklet has been duly drawn up and validated as regards its content and its appearance. Implications for practice: this educational technology is an important instrument to be used by health professionals, aiming to contribute to increase the knowledge of the relatives of children with sickle cell disease.

Keywords: Anemia, Sickle Cell; Educational Technology; Child; Family.

RESUMO

Objetivou-se elaborar uma caderneta de acompanhamento e orientação em saúde sobre a doença falciforme para familiares de crianças com essa enfermidade, e realizar a sua validação. Trata-se de estudo metodológico, realizado de maio de 2017 a fevereiro de 2018, de elaboração e validação de uma tecnologia educacional, construída a partir de pesquisa de campo prévia em hospital pediátrico do Ceará (parecer ético nº1.994.879 e nº1.955.727). A validação de conteúdo e aparência aconteceu por juízes especialistas, técnicos e de comunicação; após os ajustes, ocorreu a avaliação por representantes do público alvo. A análise foi através do Índice de Concordância. Resultados: A avaliação dos juízes técnicos e especialistas alcançou Índice de Concordância global de 0,93, caracterizando a caderneta como de boa qualidade. Os juízes de comunicação avaliaram todos os itens como superior. Quanto aos familiares, todos concordaram que a caderneta estava adequada. Conclui-se que a caderneta foi devidamente elaborada e validada quanto ao seu conteúdo e a sua aparência. Implicações para a prática: essa tecnologia educacional constitui importante instrumento a ser utilizado por profissionais de saúde, visando contribuir para o aumento do conhecimento dos familiares de crianças com doença falciforme.

Palavras-chave: Anemia Falciforme; Tecnologia Educacional; Criança; Família.

RESUMEN

Se pretendió elaborar una libreta de acompañamiento y orientación en salud sobre enfermedad falciforme para familiares de niños enfermos y realizar su validación. Método: Estudio metodológico, realizado de mayo 2017 a febrero 2018, de elaboración y validación de una tecnología educativa, construida a partir de investigación de campo previa en un hospital pediátrico de Ceará (dictamen ético nº1.994.879 y nº1.955.727). Validación de contenido y forma se produjo por jueces expertos, técnicos y de comunicación; después ocurrió la evaluación por representantes del público-objeto. Análisis por Índice de Concordancia (IC). Resultados: Evaluación de jueces técnicos y expertos alcanzó IC global 0,93, caracterizando la libreta como de buena calidad. Los de comunicación evaluaron todos los ítems como Superior. Para los familiares, todos la consideraron adecuada. Conclusión: Se evaluó la libreta por su contenido y forma. Implicaciones para la práctica: Esta tecnología educativa es un importante instrumento para profesionales de salud, con el fin de contribuir al aumento del conocimiento de los familiares de niños con enfermedad falciforme.

Palabras clave: Anemia de Células Falciformes; Tecnología Educacional; Niño; Familia.
INTRODUCTION

Sickle diseases are a serious public health problem, affecting millions of people around the world, with high mortality and morbidity rates. They are caused by a genetic change that results in the formation of a hemoglobin (Hb) S, or other mutant hemoglobins, which have different properties of the molecule of hemoglobin A.1-2

Thus, the combinations of a mutant Hb with another of type S constitute sickle diseases, such as: sickle cell anemia (Hb SS), S beta thalassemia and the double heterozygous HbSC and HbSD, the most severe being HbSS and Hb S beta thalassemia.3

Because of this mutation, red blood cells undergo a process of change in their morphological conformation, assuming the shape of a scythe, which affects the adequate blood flow through the vessels. In this way, vasoconstriction occurs, venous stasis and reduction of oxygen supply to the tissues in several organs, which promotes its progressive lesion and painful crises.4

As for the child, from the six months of life onwards it is possible to start some diseases, such as: chronic anemia, severe infectious processes, pain crises, as well as complications such as stroke, between others that can compromise multiple organs.5-6 In this way, continuous health care is needed from a very early age.

The diagnosis is made in the Unified Health System, through the National Neonatal Screening Program (PNTN), where the blood of the neonate is collected at the heel and is called the "test of the foot". In addition to hemoglobinopathies, other diseases can also be diagnosed by this test, making possible early treatment, which should be available in the public health system, in order to reduce complications and provide conditions for the affected population to achieve a better quality of life.5

Thus, because of the different clinical peculiarities of sickle-cell disease and the importance of lifelong health follow-up, it is emphasized that the relatives of these children need to be properly oriented about this disease, the necessary care, as well as about the early identification of signs of risk for complications, with a view to preventing its aggravation.

With the news of the diagnosis of sickle cell disease in the child, family members begin to deal with feelings of fear and insecurity, in the face of a process that is often unknown to them, which generates expectations of obtaining more health information about what can happen with their children and what actions they should develop.7

When symptoms and treatment begin, the family can better understand the severity of the disease and the need for intensive health care, and the importance of receiving appropriate guidelines for the prevention of complications in the child’s body.8-9

However, national and international literature has revealed that many family members and caregivers have had low knowledge about sickle cell disease, its pathophysiology, genetic inheritance, complications, necessary care, among other information.9-12

From this perspective, it is pointed out that health education aims to promote self-care in people with sickle cell disease; when infants, this care is linked to the relatives, because these people are dependent on others with greater age and knowledge. In this way, professionals must establish an educational process and preparation for both the sick and their families, related to daily activities, health maintenance, complications prevention and crisis management.13

The educational technology comprises a strategy that can be used within the health education process, helping in the mediation of the activities carried out by the facilitators, during the sharing of the information, and, to that end, involve actions that meet the needs of the target audience. technology is intended.14

In this sense, it is highlighted that the elaboration of printed technologies (such as a notebook) is intended, among other aspects, to facilitate the assistance provided by health professionals, during the orientation process for users and their families, regarding the illness, treatment, and self-care activities. Therefore, they help to standardize guidelines and help the community to better understand its health-disease process and to consciously seek out the paths to be followed for its recovery.15

However, the absence of a printed educational technology for family members of children with sickle cell disease, available in the literature, was observed. In this sense, in view of the importance of creating a strategy to increase the knowledge of these people, this research aimed to elaborate a health monitoring and guidance booklet on sickle cell disease for family members of children with this disease and validate it.

METHOD

It is a methodological research, of internal elaboration and validation of an educational technology. The methodological research aims at the realization, improvement and evaluation of an instrument or a strategy that makes possible to improve a methodology.16 In addition, this type of study seeks to elaborate, validate and evaluate instruments / techniques, aiming at the construction of a reliable instrument, that is possible its later use.17

For that, the steps based on the recommendations that have been reference in several researches in the guidance on how to develop manuals of education in health were followed.15 However, a “Situational Diagnosis” phase was included, and another was “Selection of content to be addressed in the Booklet”. In summary, the steps were: 1) Approval of the project in the Research Ethics Committee; 2) Situational Diagnosis; 3) Review of literature and documentary; 4) Selection of Content; 5) Preparation of the Booklet; 6) Internal validation.

From situational diagnosis to carnet elaboration

After approval of the project (described below), we sought to hear relatives of children with sickle cell disease in a pediatric referral service in Ceará, located in Fortaleza, in the waiting room of the specialty clinic, through individual semi-structured interviews, focusing on questions that sought to understand the main orientation needs of these people (situational diagnostic phase).

Subsequently, a literature and documentary review on the
At that moment, there was no restriction on the location of these professionals, and, in the end, there were people from different Brazilian regions, which contributed to the validation process, through various experiences on sickle cell disease; among the cities, were: Mato Grosso, Minas Gerais, Bahia, Mato Grosso do Sul, Rio de Janeiro, São Paulo and Ceará. A Brazilian judge residing in the United States, who has developed studies on sickle cell disease in that country, also participated.

This phase of validation of content and appearance took place from August to October 2017, and invitations were sent electronically or in person. After accepting and signing the Free and Informed Consent Form (ICF), the booklet was sent together with the evaluation instrument. The initial deadline for the return was 15 days, being extended by another 15 to 30 days, depending on the request of the judge.

The expert and technical judges used the same instrument, composed of two evaluation parts: the first contained items related to the analysis of the objectives, structure, presentation and relevance of the book, adapted from Oliveira(15) (for each question, the judge could mark: 1-unsuitable, 2-partially adequate, 3-suitable and 4-fully adequate); the calculation of the score was made from the amount of items that received a score between 3 and 4, being the ones with the lowest score eliminated or reviewed by the researchers. Thus, the Concordance Index (CI) = number of responses with values of 3 and 4/total number of responses.

The second part of the instrument was composed of items that assessed all subjects in a more detailed way, being adapted from Barbosa, where, for each topic covered, the judges answered "yes" or "no" as to clarity, comprehension and relevance, and, lastly, the degree of suitability (1- inadequate, 2-partially adequate, 3-adequate, 4-fully adequate).20

After the evaluation, the CI was applied to assess the proportion of judges in agreement on the aspects contained in the instrument, related to content and appearance; the items with concordance >or=0.78 were considered adequate.21-22 To quantify the level of agreement in relation to the second part of the instrument, those that reached an index equal to or greater than 80% were considered valid.20

On the other hand, the judges of communication used an instrument adapted from Doak, Doak and Root23, Suitability Assessment of Materials - SAM, evaluating the suitability of the book based on the aspects related more specifically to this professional category, such as: layout and presentation, language, graphic illustrations, motivation and cultural adequacy. According to this instrument, each evaluated item receives a score, being “0” (inadequate), “1” (partially adequate) or “2” (adequate).

Thus, following the recommendations of these authors, the sum of all the points of the communication professionals was divided by the maximum possible total score and then multiplied the result by 100, obtaining, in this way, a percentage. If this percentage was between 70 - 100%, it would mean that the material was very suitable; and more than or equal to 40% would be considered adequate.23

After these analyzes, the necessary changes were made,
according to the final score, regarding items with low scores. In addition, the observations and suggestions of the judges were also appreciated as to the need for material changes.

Following the validation of content and appearance, the analysis of the organization, appearance, motivation and learning was performed with 12 family members representing the target audience to which the book was destined, selected through non-probabilistic sampling by criteria of convenience. It was developed at the pediatric referral hospital in Ceará, mentioned above, in the waiting room of the specialty clinic in December 2017. For that, an evaluation instrument was used with four topics related to the aspects under analysis. It was considered that the book would be adequate, when a percentage of positive responses (“yes”) greater than or equal to 70% was reached; and items with negative evaluation and/or suggestions were used to reorganize the final version of the Booklet.

Ethical aspects

It should be noted that all the recommendations of the National Health Council were followed through Resolution 466/2012. The research was approved by the Research Ethics Committee of the State University of Ceará (opinion 1.955.727) and the hospital scenario of data collection (No. 1.994.879). All participants signed the ICF, being guided about the risks and benefits of the research, the possibility of being able to give up their participation at any time and that they would not have any burden.

RESULTS

After the elaboration, the booklet contained 63 pages, and from page 10 to 41 the contents of orientation to the relatives were described; from pages 42 to 60, the spaces related to the child’s health records were inserted.

The topics selected from the demands of the relatives of children with sickle cell disease, together with the findings found in the literature review (totaling only six articles on health education activities about sickle cell disease after the searches presented in the methods) were: information on human blood, definition of sickle cell disease and sickle cell trait, genetic inheritance in sickle cell disease, signs and symptoms, major complications and necessary care, health diagnosis and follow-up, treatment, bone marrow transplantation, with food, health rights and how to deal with the disease in the child’s life.

As regards the records: the child’s appointment schedule, daily medications, laboratory tests, other examinations of the child, vaccination records, health professionals’ notes, observations on the child’s health (in seizures and blood transfusions), hospitalizations, space for communication between health services and family notes.

Characterization of study participants

As to the profile of the nine specialist judges, there was a predominance of female subjects (77%). In relation to age, 66.6% were older than 50 years. The majority (77.6%) had more than 20 years of professional training, revealing judges with a greater degree of experience in their work area.

Among the basic formations, it was possible to obtain the participation of professionals from different areas of knowledge, in order to also contribute to the evaluation process, from different visions; such as: psychology, nursing, nutrition, medicine, biology and anthropology. Of these professionals, the predominance of nursing (44%).

Regarding the area of work, only one of the judges did not practice teaching activities. As for titration, three were masters, five were doctors, and one was a postdoctor. All participated in research projects on sickle cell disease and six judges had theses or dissertations on this subject. Everyone had articles and/or book chapters focusing on this disease. Thus, these aspects reaffirmed the degree of knowledge of these professionals about the area under study, as well as their wide experience in the contents presented in the book.

Of the eight technical judges, women (75%) also predominated. As for the age group, 50% were between 40 and 49 years of age. Four were doctors, one was a dentist, two were nurses, and one was a pharmacist; 75% of these professionals had more than 20 years of training. In this sense, we can also see that this group of professional judges had extensive professional experience.

In relation to the degrees, five were specialists, one was master and two were doctors; four had developed papers on the subject in the postgraduate course. Almost all were involved in groups or research on sickle cell disease (87.5%); all had participated in events and presented papers on this subject; 63% had professional experiences directly related to the care of people with sickle cell disease, and the others had health education activities about the disease.

Regarding communication judges, 57.1% were women. As for the age group, 42.9% were between 20 and 29 years old and 42.9% between 30 and 39 years old. Regarding academic training, 42.9% were Graphic Designs, 42.9% Advertising and only one participant was Marketing Analyst. The training time ranged from two to 28 years, with 57.1% having up to five years of training. The majority (71.4%) had already produced manuals, books, booklets or other widely disseminated social documents; 85.7% had experience in Art Direction; and 85.7% had already done work in the area of health or education.

As for the 12 representatives of the target public, all were mothers of children with sickle cell disease and 50% were between 18 and 24 years of age. In relation to schooling, 58.33% had completed High School and 41.67% wereIncomplete or Complete Elementary School, revealing a profile of participants with different levels, which contributed to a better process of assessing the booklet, from people with degrees of knowledge.

As for marital status, the majority were married or lived in a stable union (66.7%). Only one participant had formal employment, as a teacher, and the others had activities in their homes and care of their children (91.7%).

Content and appearance validation

As regards the evaluation carried out by the group of tech-
technical judges and experts, who have used the same instrument to validate the book on content and appearance, the following Table 1 presents the results of the first part of this instrument, with respect to the items: objectives, structure, presentation and relevance, as well as the IC achieved in each subitem evaluated.

As can be seen in the table below, all items obtained CI greater than 0.78, minimum value that should be punctuated to validate the book as a good quality material. The lowest score was CI = 0.82 and the maximum CI = 1. The overall average of the book, which was the sum of all the points reached, divided by the maximum score that could have been reached, was 0.93, revealing an educational technology with good quality and rigorously validated in content and appearance, by those professionals with high knowledge on the subject.

### Table 1. Evaluation of technical judges and experts - Instrument I. Fortaleza -CE, Brazil, 2017.

<table>
<thead>
<tr>
<th>Items</th>
<th>N</th>
<th>CI</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Objectives</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 Are consistent with the guidance needs of people with sickle cell disease and their family members</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>1.2 Promotes behavior change and attitude</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>1.3 It may circulate in the scientific field in the area of sickle cell disease</td>
<td>14</td>
<td>0.82</td>
<td></td>
</tr>
<tr>
<td><strong>Structure and Presentation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.1 The Handbook is appropriate for people with sickle cell disease and their family members</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2.2 The messages are presented in a clear and objective way</td>
<td>16</td>
<td>0.94</td>
<td></td>
</tr>
<tr>
<td>2.3 The information presented is scientifically correct</td>
<td>14</td>
<td>0.82</td>
<td></td>
</tr>
<tr>
<td>2.4 The material is appropriate to the socio-cultural level of the proposed target audience</td>
<td>14</td>
<td>0.82</td>
<td></td>
</tr>
<tr>
<td>2.5 There is a logical sequence of proposed content</td>
<td>16</td>
<td>0.94</td>
<td></td>
</tr>
<tr>
<td>2.6 The information is well structured in agreement and spelling</td>
<td>14</td>
<td>0.82</td>
<td></td>
</tr>
<tr>
<td>2.7 Cover, back cover, summary and presentation information are consistent</td>
<td>15</td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>2.8 The illustrations are expressive and enough</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Relevance</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.1 Topics cover key aspects that need to be strengthened</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>3.2 The material proposes to the reader to acquire knowledge about sickle cell disease</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>3.3 The material addresses subjects necessary for the prevention of complications in sickle cell disease and guidelines for appropriate decision-making in the face of crises</td>
<td>15</td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>3.4 It is suitable for use by any professional or health worker in their educational activities</td>
<td>15</td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>3.5 The material contains the necessary aspects to records of health care provided to a person with sickle cell disease</td>
<td>16</td>
<td>0.94</td>
<td></td>
</tr>
<tr>
<td>3.6 The material provides support to facilitate communication between health services about the care provided to these people with sickle cell disease</td>
<td>17</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Global Booklet Concordance Index</strong></td>
<td>268</td>
<td></td>
<td>0.93</td>
</tr>
</tbody>
</table>

Source: Elaborated by the authors. Caption: n = number of judges with answers “3” (adequate) or “4” (fully adequate).
Regarding the second part of the assessment instrument, carried out by the subjects of the booklet, everyone obtained a high level of agreement among the judges as to the clarity, comprehension and importance of the subjects being dealt with in the book (ranging from 88.24% to 100%). Regarding the degree of appropriateness of the topics, nine had a CI between 82% and 100%, and only two subjects presented low scores (CI=65% in subjects related to the general explanation about sickle cell disease and CI=76% in subjects related to treatment).

Among the main recommendations provided by these judges, the following stand out in Chart 1:

All the suggestions presented in Chart 1 were accepted by the researchers, based on the relevant scientific literature, especially those related to the topics with lower CIs, in order to make them more appropriate. However, some observations have not been adhered to, as they are contrary to national and international evidence, do not bring greater benefits to the book and/or represent occasional opinions/suggestions.

Regarding the evaluation developed by the communication judges, all classified the booklet as Superior (scores above 20 and percentage higher than 70), revealing the adequacy of the educational technology elaborated, as shown in the Table 2.


<table>
<thead>
<tr>
<th>Chapters of the Booklet</th>
<th>Suggestions from technical judges and experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Suggestions</td>
<td>- Revision of Portuguese and grammatical; Review paragraph formatting;</td>
</tr>
<tr>
<td></td>
<td>- Add chapter with guidelines on the school;</td>
</tr>
<tr>
<td>And what, after all, is sickle cell disease?</td>
<td>- Keep only the term hereditary or genetic in the phrase “it is a genetic and hereditary disease”, because they are synonymous;</td>
</tr>
<tr>
<td></td>
<td>- Replace “erythrocytes other than normal” by a text that includes the types of hemoglobin present, so as not to stigmatize the phrase;</td>
</tr>
<tr>
<td></td>
<td>- Include in the texts hemoglobin A and S or another mutant, to facilitate explanation, especially in the context of sickle cell trait;</td>
</tr>
<tr>
<td></td>
<td>- Include the situations that lead the red blood cells to take the form of sickle;</td>
</tr>
<tr>
<td>How Can One Get Sickle Cell Disease</td>
<td>- Replace “from parents to children” with “an illness that children inherit from their parents” because the first version is criticized by people with sickle cell disease;</td>
</tr>
<tr>
<td></td>
<td>- Redo image.</td>
</tr>
<tr>
<td></td>
<td>- Change the title of the chapter by “How can one be born with sickle cell disease”;</td>
</tr>
<tr>
<td></td>
<td>- Improve the description of the sickle cell trait. Include explanation about mutant genes.</td>
</tr>
<tr>
<td></td>
<td>- Remove the word “carrier” from the subtitles.</td>
</tr>
<tr>
<td>What complications can happen?</td>
<td>- Improve the image of the girl with symptoms of stroke. Include text that talks about the importance of transcranial Doppler in preventing stroke. Replace the word “infarction” with a clearer one with brain injury;</td>
</tr>
<tr>
<td></td>
<td>- Improve the text that talks about complications in the spleen, to facilitate the understanding. Include an image that explains the correct way to palpate this organ. Replace the word “worse” with “more serious”.</td>
</tr>
<tr>
<td>How is the treatment?</td>
<td>- Add the effects of hydroxyurea;</td>
</tr>
<tr>
<td></td>
<td>- Include transcranial Doppler examination;</td>
</tr>
<tr>
<td>Caring for food</td>
<td>- Improve the text, with the help of nutritionists working on sickle cell disease;</td>
</tr>
<tr>
<td></td>
<td>- Reorganize text related to iron and vitamin C, to facilitate understanding;</td>
</tr>
<tr>
<td>Child Health Records</td>
<td>- Reformulate table with exams;</td>
</tr>
<tr>
<td></td>
<td>- Add observations from the school;</td>
</tr>
<tr>
<td></td>
<td>- Include registration chart for Iron chelation scheme and adverse events;</td>
</tr>
</tbody>
</table>

Source: Elaborated by the authors.
Minor remarks have been made by some, including suggestions for improving the book, such as: leave the title on the cover with words at the same time; change the children's place on the cover and approach the characters so that they seem to be a family; improve text formatting, aligning left in “justified” mode; redo the summary in order to favor the reading, without the icons in the form of red cells, putting them as an illustration and not as page identification; among others.

Thus, the contributions of these professionals were followed in order to improve the book and, after the necessary adjustments, it was evaluated by the representatives of the target public. All of them (100%) agreed that the book was properly organized, through a cover that attracted the attention of the readers, a content properly sequenced and through an organization that facilitated the reading and understanding of the contents.

For all participants the language was also adequate, with easy-to-understand phrases, use of simple words and explanations for the difficult ones. They also stated that they were able to understand all the information in the book.

As for appearance, everyone agreed that the illustrations facilitated the understanding of the text, were interesting and were easy to understand. In relation to motivation and learning, everyone stated that the contents of the book were interesting and motivated reading; in addition, all stated that they had learned new information and that they were encouraged to think more about the child's health and the necessary care.

Concerning the suggestions, only one participant requested that further information on the type of sickle cell disease HbSS was described, since, according to her, it was the most important type because of its severity. However, it was not possible to expand information on this specific type of disease, since the booklet aims to provide general information on all sickle cell diseases without specific approaches.

All the mothers brought positive remarks about the book, as you say:

I found it very important, because I had already searched in other books, but it was not easy to understand, and in that book simplified, the figurines helped and understanding as well. (PA1)

[...] I had a lot of doubts too, only the little I read already gave to clear the doubts, I think it was good for the mothers to receive to clear the doubts (PA5).

Thus, the family members reaffirmed the importance of this educational technology in the orientation process, both for them and for other relatives. Thus, the carnet was duly evaluated by the target public, and the internal validation process was concluded.

## DISCUSSION

The literature has revealed the importance of educational technologies that are built based not only on the researchers' opinion and experience. Thus, during the selection of the content to be approached in these materials, it becomes essential to seek to understand the target audience for which it is intended and its real needs. Therefore, a situational diagnosis, as was done in the present study, tends to contribute to the quality of the chosen content.

Regarding the process of validation by professionals and workers from different areas of knowledge, it was observed that it was of great relevance for the improvement of the book, since it was possible to obtain opinions and different views on the contents addressed, which would probably have been incipient with the restricted participation of a professional group.

Other research has reinforced the importance of this expansion in the diversity of professional judges as a contributing factor to the formation of a more complete educational technology. For a better evaluation process, it is suggested that it be performed by professionals from different areas of knowledge, such as educators, health professionals and social communicators, so that the validation is done in a team, valuing different perceptions about the same subject matter.

In the process of validation by technical judges and specialists, the objectives (related to the orientation needs of people with sickle cell disease and their relatives), the structure and presentation of the book (involving the adequacy of writing, logical sequence, spelling, illustrations, among others aspects), as well as their relevance to the topics covered, obtained CI between 0.82 and 1, which revealed a concordance among the judges regarding the quality of the book.

The concordance rates considered acceptable are variable and the literature recommends that they be between 70-100%, and that in this research was used a value greater than or equal to 0.78 (CI> 0.78), since it is estimated as a value which reveals good property of the material elaborated.

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**Table 2. SAM score of the communication judges. Fortaleza-CE, Brazil, 2017.**

<table>
<thead>
<tr>
<th>Judge</th>
<th>SAM Score</th>
<th>Percentage</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Judge 1</td>
<td>27</td>
<td>96%</td>
<td>Superior</td>
</tr>
<tr>
<td>Judge 2</td>
<td>27</td>
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<tr>
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<td>Judge 4</td>
<td>21</td>
<td>78%</td>
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</tr>
<tr>
<td>Judge 5</td>
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<tr>
<td>Judge 6</td>
<td>26</td>
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<td>Superior</td>
</tr>
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<td>Judge 7</td>
<td>26</td>
<td>93%</td>
<td>Superior</td>
</tr>
</tbody>
</table>

Source: Elaborated by the authors.
The subitems that achieved lower CI scores (0.82) were: “may circulate in the scientific milieu in sickle cell disease”; “The information presented is scientifically correct”, “the material is appropriate to the socio-cultural level of the proposed target audience”, and “the information is well structured in agreement and spelling.” In this way, the judges’ recommendations were followed, and the content was revised as regards the scientific basis, the cultural context of the target audience and revised grammatically.

The reformulation of the book was also carried out based on the second part of the validation process of the expert and technical judges, where two topics presented low scores, as previously described. In general, the main contributions, as described in Chart 1, were related to the substitution and addition of some terms, modification of some illustrations and withdrawal of stigmatizing words or phrases, in order to facilitate the understanding of the target public regarding the guidelines presented. The requests submitted were accepted, including the insertion of a chapter on the guidelines on the school, the addition of a page to record information in this environment and another on the scheme of chelation of iron and adverse events.

Despite the various suggestions, it should be noted that the overall mean of the booklet was high (0.93). In this sense, other researches have also found similar results, where although the educational materials were well evaluated by the judges, they made contributions and observations in order to improve the quality of the material for the target audience.27-28

As for the evaluation made by the judges of communication, it can prove the pertinence of the organization, layout, illustrations and other graphical compositions of the book, as well as the adequacy of the written text, according to the vision of professionals who act directly with these visual concepts. Other research has also emphasized the importance of their participation in the process of validating educational technologies.29-31

After the contributions of this group of professionals were implemented, the booklet was printed and delivered to the families of children with sickle cell disease, to complete the evaluation process.

This analysis is seen as a subjective way of validating an educational technology, however it includes the evaluation of important points such as: clarity, readability, form of presentation and understanding of the instrument. At this stage, there should be participation of representatives of the target audience, that is, people with a convergent profile for the technology developed.14

Through this evaluation, it was observed that all the family members agreed with the quality of the book, which was confirmed by their reports, where it was noticed that all emphasized that the educational technology clarified many doubts that they possessed, to present a language simpler, along with adequate and clear illustrations, which contributed to a better understanding of the information about sickle cell disease. It was also highlighted the importance of this material to other relatives, as it would be very useful to help other people who have had little access to guidelines on this disease.

In its recommendations on the development of educational manuals, the author stresses that it is essential to transform the scientific language described in the literature into an easy-to-understand reader, insofar as these tools must be created in order to strengthen the guidelines to the patients and their families, being necessary the existence of a language that attends to the different levels of schooling of the population.27

Differing from our findings, another validation study with adolescents found an agreement of 88.4% among the participants, representing the target audience, to the extent that many people reported not feeling at ease, or only in part, to read the elaborate primer.27

On the other hand, a validation research of an educational booklet for healthy eating during pregnancy, showed that the material elaborated was considered adequate by the participating women, however, the authors pointed out that the low level of schooling seemed to have contributed to the smallest number of suggestions.32

In the study developed by Rocha, Cioff and Oliveira4, these authors observed that one of the strategies that can be used in the search to increase the knowledge of family members/caregivers of children with sickle cell disease is the use of written materials that are culturally adapted and sensitive to the target audience of the educational process through of simple language and easy understanding to these people.

Thus, the present research was able to reach this goal, inasmuch as the book was well received by family members, who emphasized their contributions to increase their knowledge about this disease and the necessary care for the child.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

It has been revealed the importance of relatives of children with sickle cell disease to be advised about this disease and its repercussions of the infant’s body, which will require lifelong care and constant health monitoring, aiming at avoiding complications and even early deaths.

Faced with this demand, a health guidelines booklet was elaborated, based on the needs evidenced by the family members, along with the discussions in the literature. This educational technology also contains spaces for various health records, such as exam results, professional guidelines, observations during hospitalizations, pain crises, among other aspects, allowing the maintenance of this information along the therapeutic itineraries traced by the child.

In order to guarantee the quality of the book, it has undergone a validation process regarding its content and its appearance, through a thorough multi-professional evaluation, through masters and experts in the subject (expert judges), and professionals who work in the assistance people with sickle cell disease or health education (technical judges), where it reached a global CI of 0.93, revealing the quality of the material; and also by means of the evaluation by workers in the media area (communication
judges), where everyone classified the passbook as Superior (score higher than 70% in the SAM score).

After this validation, the book was reorganized based on the judges’ suggestions, in order to make it more scientifically adequate, as well as clearer and easier for readers to understand. Later, it was evaluated by family members of children with sickle cell disease, where all agreed that the organization, language, appearance, motivation and learning were adequate, in addition to highlighting the importance of the material to clarify their doubts and other relatives, simple and illustrations that help the understanding about the content covered.

Therefore, it is suggested that this booklet be implemented in the practice of health professionals of different levels of care, functioning as an important tool to support their health education activities, contributing to the care of children with sickle cell disease and strengthening understanding of the family about this process of illness, who may make use of it at home, whenever they feel the need to remember and clarify information.

However, the present study presented limitations, since it was not possible to prepare the book for other sickle-sick people, such as adolescents, adults and pregnant women. Thus, there is a need to develop new studies aimed at meeting the specific needs of these people, in other phases of life, in addition to children. On the other hand, the results discussed in this manuscript could foster the development of new researches and health education strategies, functioning as a basis to start new work on the subject.

REFERENCES


2. Fernandes Q. Therapeutic strategies in Sickle Cell Anemia: The past strategies, functioning as a basis to start new work on the subject. Foster the development of new researches and health education.


Sickle cell disease booklet
Figueiredo SV, Moreira TMM, Mota CS, Oliveira RS, Gomes ILV


* Research extracted from the Thesis “Creation and validation of a health guidance booklet for family members of children with sickle cell disease”, defended in 2018 in the Postgraduate Program in Collective Health of the State University of Ceará (UECE).