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ORIGINAL ARTICLE

Educational technology for caregivers of children and teenagers dependent on special care in the home

Tecnologia educativa para cuidadores de crianças e adolescentes dependentes de cuidados especiais no domicílio

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ABSTRACT

Educational material can promote significant results in health promotion. However, the contribution of these materials depends on the preparation process and the forms of communication used to transmit the information. This study aimed to develop educational technology for the caregivers of children and teenagers dependent on special care in the home. This is a methodological study carried out in five phases: content systematization, choice of illustrations, composition of the booklet, validation of the booklet by judges, and caregiver validation. The booklet was prepared based on an integrative review of the literature and through interviews with 19 caregivers. The content validity rating among the judges was 0.99, indicating an excellent degree of agreement. The semantic validation by the caregivers obtained an agreement percentage of 100%. Given the results, it can be concluded that the educational technology had an excellent level of acceptance, being able to contribute to the care of bedridden children and teenagers.

Descriptors: Home Nursing; Disabled Children; Caregivers; Nursing; Educational Technology.

RESUMO

Materiais educativos podem promover resultados expressivos na promoção da saúde. No entanto, a contribuição desses materiais depende do processo de elaboração e das formas de comunicação utilizadas para transmitir as informações. O estudo teve como objetivo desenvolver uma tecnologia educativa para cuidadores de crianças e adolescentes dependentes de cuidados especiais no domicílio. Estudo metodológico realizado em cinco fases: sistematização de conteúdo, escolha das ilustrações, composição da cartilha, validação da cartilha por juízes e pelos cuidadores. A cartilha foi elaborada com base em revisão integrativa da literatura e por entrevistas com 19 cuidadores. O índice de validade de conteúdo entre os juízes foi de 0,99, indicando ótimo grau de concordância. A validação semântica pelos cuidadores obteve-se um percentual de concordância de 100%. Diante dos resultados conclui-se que a tecnologia educativa teve excelente aceitação, podendo contribuir para o cuidado de crianças e adolescentes acamados em domicílio.

Descritores: Assistência Domiciliar; Crianças com Deficiência; Cuidadores; Enfermagem; Tecnologia Educacional.

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INTRODUCTION

Care practices for children and teenagers have been undergoing changes every year, as a result of technological, medicinal and technical advances. These changes substantially increase the survival rate of premature children with very low weights. However, this survival is accompanied by certain morbidities that often require specialized and continuous care.

Thus, as technological evolution increases life expectancy for such children, it ends up generating a new group of children with chronic health conditions, who are, sometimes, dependent on technology. In Brazil, this group of children was named Children with Special Health Requirements (Crianças com Necessidades Especiais de Saúde) (CRIANES). These children demand special healthcare, whether temporary or permanent, albeit with a plurality of diagnoses and dependence on healthcare services[1,2].

In Brazil, studies on the prevalence of children that need special healthcare remain incipient. However, research carried out in the states of São Paulo, Rio de Janeiro and Rio Grande do Sul, demonstrated a prevalence of 25.3% of CRIANES in children under 12. Of these, 9% required follow-up for mental or physical health problems, 5% were in rehabilitation and 4.4% had some kind of functional limitation or incapacity[3].

As a result of the chronicity of these pathologies, home care has arisen as a way of achieving hospital discharge, as it is understood that the family, by being the central element for the well-being of these children, is the preferential care unit. However, in order for care to be effective and safely provided in the home, health promotion actions that aim to increase family participation in care are necessary[4].

Such actions reinforce that patient safety is the responsibility of all those involved, and goes beyond the safety of only the patient, to include the safety of professionals, family members and the community. This type of action increases family involvement in care and can improve the relationship between healthcare professionals, patients and families[5].

Within this context, the arrival of a child with special needs into the family environment causes changes in their daily routine, with family members suddenly needing to provide care that would previously only occur in the hospital unit[6]. It is imperative to state that such a family requires continuous guided attention from healthcare services regarding their needs, so as to provide better quality of life to this population.

Given the need for continuity in the provision of care, home care programs have been growing in the last decade with the refinement of the Home Care Systems (Sistemas de Atenção Domiciliar) (SAD). These systems manage and operationalize certain programs, such as the Home Assistance Program (Programa de Assistência Domiciliar) (PAD), the Home Respiratory Assistance Program (Programa de Assistência Ventilatória Domiciliar) (PAVD), and the Better at Home Program (Programa Melhor em Casa), which consists of a Multi-professional Home Care Team (Equipe Multiprofissional de Atenção Domiciliar) (EMAD) and a Multidisciplinary Support Team (Equipe Multidisciplinar de Apoio) (EMAP). These programs are aimed at early hospital discharge, which is reflected in the reduction of costs and the demand for hospital care, based on humanization of healthcare through closer contact of the team with the patient and their family members.

To assist in this adaptation process, the educating role of health professionals, especially nurses, is essential in the autonomy of families in the process of caring for children dependent on special healthcare[7]. The communication of professionals with families can be facilitated through tools that assist in the reinforcement of care for this population.

Therefore, educational technologies, in booklet form, are considered indispensable tools for increasing knowledge, satisfaction, adherence to treatment and self-care in various populations, such as carriers of chronic diseases[8], children with gastrostomy[7] and the elderly[9]. Nevertheless, the production of technology that assists in the home care of children with special needs and their families remains limited, indicating the need for production that enhances this mode of care, as well as contributing to safe and high-quality integral care[10].

In light of the above, this study aims to develop an educational booklet for caregivers with the intention of improving the safety and quality of the care provided to bedridden children and teenagers with irreversible diseases.

OBJECTIVE

The objective of the study was to construct and validate an item of educational technology for caregivers on the care of children and teenagers dependent on special care in the home.

METHODOLOGY

This is a methodological study carried out in five phases: content systematization; illustration creation; booklet composition; validation of the booklet by judges; and validation of the booklet by the caregivers[11].

The research was developed in a municipality of the metropolitan region of Fortaleza, Ceará, in the period from March 2016 to December 2017. The Multi-professional Home Care Team (MHCT) of the referred municipality attended a total of 60 patients a month during this period, of whom 19 were bedridden children and teenagers requiring specialized care. The MHCT consists of a doctor, a physiotherapist, a nurse, and nursing technicians.

The first stage of booklet construction took four months. Content systematization was carried out based on interviews with 19 caregivers of bedridden children and teenagers and through a literature review composed of protocols[12,13], Manuals of the Ministry of Health[14-18] and scientific articles[19-21].

The interviews were carried out with all the caregivers during home care visits, and they lasted from 15 to 20 minutes. The objective of the interviews with the caregivers was to identify the clinical profile of the bedridden children and teenagers, identify the socioeconomic profile of the caregivers, and the main difficulties they experienced during the provision of care.

In the second phase, illustration creation, the author developed all the figures that would represent the procedures carried out in the home together with a graphic designer. Part of this stage was consultation of a book on nursing fundamentals[22] and operational procedures[16-18].

In the third phase of the study, booklet composition, the content was organized by the researcher, the physiotherapist and their supervisor, and the nurse, into the form of a script. Each care orientation accompanied its respective figures. The doubts of the designer, as a non-specialist on the subject, were used as one of the criteria to make the illustrations more intuitive and improve reader understanding.

In the fourth phase, an initial version of the booklet was emailed to 22 judges, who were specialists in the content, and graphic design technicians[23]. Of these, 21 judges responded, 19 being specialists in the content and two technical judges. The judges were selected for convenience, based on a search on the Lattes Platform, according to the following criteria: having at least five years experience in home care, conducting research and/or teaching in the area of child and teenage health and home care; and for the technical judges, having experience in the production of graphic art. For each category, minimum scores of five and three points, respectively, were considered.

After agreeing to participate in the study, the judges were emailed two copies of the Informed Consent Form, the booklet, and a questionnaire to evaluate the content, language, designs and layout, using a Likert scale with scores from 1 to 4; whereby, 1 — not relevant or not representative, 2 — item requires a lot of revision to be representative, 3 — item requires a little revision to be representative, 4 — item is relevant or representative[24].

During this phase, the researcher had the opportunity to meet the specialist judges in person during a national training course on home care with the participation of professionals from all over Brazil, conducted in São Paulo. The judges returned their signed consent forms and completed questionnaires with their revision suggestions at this time.

The Content Validation Index (CVI) was used for content validation. It measures the proportion or percentage of judges that are in agreement on certain aspects of the instrument and its items. For the material to be considered valid, the instrument should achieve a result greater than or equal to 0.80[25].

In the fifth and final phase, semantic evaluation of the educational material was carried out in the home with the same caregivers from the first phase of the study. The final sample at this stage was composed of 17 caregivers, as two children had passed away during the booklet construction process. In this stage, a questionnaire composed of nine items was used; seven questions were on understanding of the addressed themes with responses ("No", "Very little", "Most of it" and "Yes"), and two open questions on the general opinion in relation to the material and suggestions for improving the booklet[23].

To evaluate the degree of agreement in the semantic analysis, agreement percentages were used (agreement %=number of participants that marked "most of it" and "yes"/ total number of participants × 100). For the present study, values above 80% were considered an acceptable rate of agreement[23].

The study followed Resolution 466/2012 and was approved by the Research Ethics Committee of the university to which the researcher is connected, with decision number 1.891.564 and CAEE 62247116.6.0000.5534.

RESULTS

Presentation of the results follows the booklet construction phases. In the first phase, an interview was carried out to identify the socioeconomic profile of the caregivers and the clinical profile of the bedridden children and teenagers attended by the MHCT.

A total of 19 children and teenagers and their respective caregivers participated in the study. Of the children, 68.42% were male, in the age range from zero to six years (47.37%) and from 10 to 19 years (47.37%). The most frequent diagnosis was Cerebral Palsy by hypoxia with 57.89%, followed by myelomeningocele with 21.05%. Among the most present comorbidities, convulsions predominated, being present in all but one of the patients.

In relation to the birth history of the patients, 63.16% were born through normal childbirth and were full-term (68.42%). Regarding the use of additional equipment, gastrostomy was the most frequent (21.05%), followed by intermittent bladder catheterization (15.79%). Supplementary oxygen (5.23%) and tracheostomy (10.56%) were also present.

Most of the caregivers were female and were the patients' mothers (89.47%), less than 40 years of age (73.7%), married

or in stable union (73.7%), and with incomplete Primary Education (36.84%).

The socioeconomic and demographic profile was evaluated using family income, type of residence, number of people residing in the same home, and receiving social welfare. The income of the evaluated families was one minimum wage (63.16%), the welfare payment or pension of the child or teenager being the only income, except in one case in which the father was the provider of the house. Most of the families (68.42%) lived in their own home in an urban area (47.37%).

After collecting the sociodemographic information, the researcher asked the caregivers what the main types of care they would like to receive were. Based on this question, the themes developed in the booklet emerged as follows: Hand Sanitization, Oral Hygiene, Cleaning of the Environment, Cleaning of Materials, Bodily Hygiene, Nasal Hygiene, Change in Decubitus, Tracheostomy, Tracheostomy Aspiration, Cleaning of the Tracheostomy Subcannula, Aspiration of the Upper Airways (Nose and Mouth), Daily Exercise, Care with Tube Feeding, Care of Nasogastric Tube (NGT) and Gastrostomy (GTT), and Intermittent Bladder Catheterization.

The second phase of the study, construction of the educational material, resulted in the booklet, printed double-sided in color, in A5 size. The booklet had a total of 26 pages, including 85 figures for 14 care actions (Figure 1).

Validation of the booklet by specialist judges

In the third phase, the booklet was sent for validation by specialist judges and technicians. Nineteen professionals from various areas of Nursing (36.84%), Physiotherapy (26.32%), Medicine (26.32%), Psychology (5.26%), and Odontology (5.26%) acted as content judges, with a predominance of females (78.95%). The age range varied from 29 to 59 years, with time working in their respective areas ranging from five to 28 years.

Regarding professional qualification, 52.63% of the judges were specialists, 36.84% had Master's degrees and 10.53% had doctorates. The areas of study were Child and Adolescent Health (52.74%), Neonatology and Pediatrics (26.32%), Clinical Nutrition in Infancy (10%), Infant Development (5.26%), Public Health, Home Care and Dental Surgeon Specialist in Special Patients (5.26%).

The professionals worked in areas of healthcare and the coordination of home care programs in the following Brazilian states: Ceará, São Paulo, Bahia, Minas Gerais and the Federal District.

Regarding the technical judges, two professionals from the area of graphic art development participated, both of whom were male, working in the area for 13 and 17 years.

Regarding content validation, the CVI for the booklet was calculated as a whole and for each evaluated domain: content, language, design and layout. The total CVI of the booklet was 0.99. For language, the CVI varied from 0.95 to 1.0. These values demonstrate that there was a strong degree of agreement between the judges (Chart 1).

Chart 2 shows the rate of agreement between the judges for design and layout. Of the 11 items evaluated, 10 obtained a value of 1.0, indicating an optimal level of agreement between the judges.

All the judges made observations and most of the suggestions were included. The general opinion of the judges demonstrated the importance of the originality of the booklet. The language was considered easy to understand, with some points that were corrected according to the suggestions.

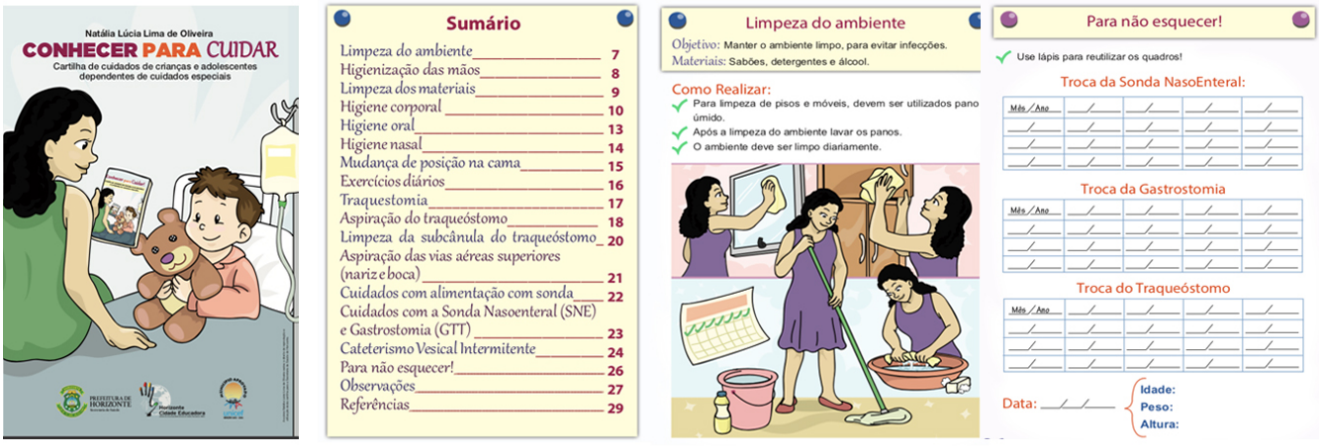

Figure 1. Page sequence from left to right: Cover with title; Page 1: Table of Contents; Page 2: orientations on cleaning the care environment; and the last page with space for the caregiver to insert information on equipment changes.

The suggestions related to the content were remove commercial names, and describe and/or alter the periods for changing equipment. The modifications were carried out according to the pertinent literature and the financial adequacy of the families. As for the language-related modifications, the most significant alteration was in relation to the title, which prior to the judges' evaluation was "Bedridden children and teenagers". This was substituted for "Children and teenagers dependent on special care".

Most of the items in the booklet were considered excellent, and many professionals emphasized that the information it contained would be of great assistance for the maintenance and improvement of home care. The modifications in relation to the design and layout were partly included, especially regarding the clarity of the figures. The drawings needed to describe the actions without the caregiver necessarily knowing how to read.

Semantic analysis of the booklet

Of the 19 caregivers that participated in the first phase of the study, two did not continue as one child and one teenager passed away during the period of booklet construction and validation by the specialist judges.

According to Chart 3, all seven of the items evaluated by the caregivers obtained 100% agreement. Therefore, the booklet was considered relevant to the caregivers with bedridden children and teenagers, as shown in the responses reported by the caregivers.

Chart 1. Content Validation Index for each item in the Booklet for Content and Language.

1. Content	CVI
1.1 The information presented is in accordance with current knowledge/literature.	0.95
1.2 The text is presented clearly and objectively.	1.00
1.3 There is a logical sequence to the content presented.	1.00
1.4. The information is appropriate to the target-demographic.	1.00
1.5 The information is satisfactory for promoting knowledge on care of bedridden children/teenagers.	1.00
2 Language	**CVI**
2.1 The information presented is clear and understandable.	0.95
2.2 The wording corresponds to the level of knowledge of the target-demographic.	1.00
2.3 The information is in agreement with the spelling.	1.00
2.4 The script is attractive.	1.00
2.5 The title of the booklet is interesting and appropriate.	0.95

Source: elaborated by the authors.

Chart 2. Rate of agreement for each item in the Booklet for Design and Layout.

3 Design	Rate of agreement
3.1 The illustrations are pertinent to the content of the material	1.00
3.2 The illustrations are consistent with the related texts.	1.00
3.3 The number of illustrations is sufficient	0.95
3.4 Presentation of the themes and situations is sufficient.	1.00
3.5 The illustration legends are appropriate and assist the reader in understanding the image.	1.00
4 Layout	
4.1 Presentation of the booklet is attractive.	1.00
4.2 Presentation of the booklet is logically organized.	1.00
4.3 Visual composition of the illustrations is attractive and well-organized.	1.00
4.4 The content is presented with lettering in an appropriate size and font for reading.	1.00
4.5 The contrast between different colors is appropriate.	1.00
4.6. The number of pages is adequate.	1.00

Source: elaborated by the authors.

All the caregivers reported the importance of having material that provided them with assistance in the care of a child or teenager. Below are some of the opinions regarding the booklet.

> *I liked the booklet, for sure. I will improve my care even more. Everything here is important. Caregiver 4*

> *The figures are very important, because there are people that don't know how to read. I liked everything, I'm interested in knowing [what to do]. Caregiver 9*

> *I really liked it, the part about how to lay the child, especially because of the situation of my child. Caregiver 12*

> *I liked the part on the feeding tube and the order for washing during the bath, starting with the head. I didn't know that. Caregiver 16*

DISCUSSION

The present study aimed to construct a booklet for caregivers of children and teenagers dependent on special care. To achieve this objective, initially, the profile of the children and teenagers, as well as that of the caregivers was identified through interviews. Subsequently, scientific evidence on the identified requirements was consulted.

Identification of the profile of the patients and their caregivers, prior to developing educational technology, is an essential stage for the construction of material aimed at the real needs of the final consumers of such technology. The participation of the patient and their relatives makes the process more democratic and transparent and is a more efficient way of stimulating them to adhere to the use of the developed technology and, consequently, participate in the care[26].

Thus, it was detected that the profile of the children and teenagers in the study was similar to that of children and teenagers dependent on mechanical ventilation in studies developed in the municipality of Belo Horizonte and in the state of Paraná[10,27].

Regarding the caregivers' profile, the results were similar to another study developed with caregivers of dependent patients, which showed that of 67 caregivers, 92.5% were female, with a mean age of 54.7 years[28]. These results show that the care of these patients, bedridden in the home, is carried out by the maternal figure of the family, being the mother or grandmother, who often left aside their own study or work activities to totally dedicate themselves to the care of the patient.

These data corroborate the results of a study developed in Paraná with the families of Children with Special Health Requirements. The research showed that the main caregiver generally abandoned their job to dedicate themselves exclusively to the child. As challenges in the care of these children, the families emphasize the caregivers' lack of preparation for home care, the absence or limitation of support services, and the fact that society is unprepared to receive/accept a child with multifaceted, complex care into social interaction[29].

Furthermore, the fear and insecurity associated with the arrival of the child requiring chronic care in the home can generate great alterations in the family's daily routine, which needs to be restructured to provide all the necessary continuous care to the child, which is a challenging situation for the family members[30].

Decree GM/MS nº 825 of April 25th 2016, advocates qualification of the caregiver to enhance healthcare actions, aiming at humanization, fostering and socialization of the demands inherent to the care process[31]. Most of the care developed in the home is performed without the presence of professionals. Thus, family members and caregivers need to be comfortable with the proposed treatment and able to carry out routine procedures, enabling continuity and good-quality care. Therefore, caregiver training is essential[5].

Given the importance of the participation of the subjects in the development of educational material, it was opted to

Chart 3. Agreement percentage on the care in regard to the booklet items.

Item evaluated by the caregivers	Agreement %
1. Was the information in this booklet important to you?	100
2. Did this booklet increase what you know about care of bedridden children/teenagers?	100
3. Was this booklet easy to understand?	100
4. Are the illustrations in the booklet interesting?	100
5. Are the colors of this booklet attractive?	100
6. Is there an adequate number of pages in this booklet?	100
7. Did you feel motivated to read this booklet until the end?	100

Source: elaborated by the authors.

question the participating caregivers as to which care activities they would like to receive printed information about. Thus, they mentioned the 14 items that were addressed in the educational booklet. This participation makes the material objective and aimed totally at the requirements of the research subjects.

Based on the needs of the caregivers, a review of manuals and standard operating procedures, as well as articles with relevant scientific evidence, was carried out. Scientific rigor brings important contributions for the researcher, for academics, for the team of professionals, and for the patients and their family members. However, the language of the information should be accessible to all levels of society, regardless of education.

The booklet needs to be attractive, objective, easy to understand, and should meet the specific requirements of a determined health situation, so that the people feel stimulated to read it. Therefore, it is important to seek to illustrate the orientations in a relaxed fashion that facilitates understanding, given that, for some people, the illustrations assist in the understanding of the text[32].

In the stage of validation with the specialists, the booklet was evaluated by professionals from various healthcare areas and from different regions of Brazil. The material achieved a total CVI of 0.99, demonstrating that there was strong agreement between the judges. Values above 0.78 are considered good evidence of content validation[23].

The present study involved professionals from other states of Brazil and the researcher had the opportunity to meet them at a refresher course on home care. As such, the content of the developed material can be considered valid at a national level, and could be used by healthcare teams from all over Brazil.

The evaluation by professionals from different areas is the moment at which it can really be said that the material is being constructed by a team, valuing the various opinions and points of view on the same theme. The validation stage with specialist judges is also mentioned in other studies as being of great relevance for refining the material to be validated. Their contribution makes it more effective and attractive, due to the suggestions in reference to the reformulation and exclusion of information, the substitution of terms, and the reformulation of illustrations[11].

Regarding the validation of the caregivers, all of the items in the booklet obtained an agreement percentage of 100%, demonstrating that the information in the booklet was important, the content and the illustrations were easily understood, the colors were attractive, the number of pages was adequate, and that they felt motivated to read the booklet. It is therefore understood that the participation of patients and their family members is a necessary attitude, essential for the development of educational technology, since the main focus of health education should be the patient and their family[11,32].

Although the results of the study demonstrate that the content of the educational technology was valid for healthcare professionals and was considered to be easily understood by the target demographic, it is believed that further studies proving the clinical validity of this material in different regions are necessary. This is because the intention of the booklet is to improve the safety and quality of the care provided to bedridden children and teenagers with irreversible diseases.

The limitation of the study refers to the collection of information with caregivers from a single region of the country, which may not represent the reality of this profile of patients and caregivers in other regions of Brazil. Nevertheless, it is believed that the final product of this study, arising from professional Master's research, can stimulate professionals in diverse areas of knowledge to develop research on themes that meet the true requirements of the work environment.

CONCLUSION

The Know to Care (Conhecer para cuidar) booklet was considered valid in its content and appearance by specialist judges, technicians and the target demographic.

The interviews with the caregivers made it possible to identify the main care difficulties. These themes were addressed with self-explanatory illustrations, accompanied by captions and additional information with clear, objective, and easily understood language, confirmed in the semantic validation.

The validation with the judges was essential for the quality of the produced material, besides having been an opportunity to integrate various professionals from diverse areas and regions of Brazil. This makes it possible to use the booklet in other states, through the local reality, as it contains standardized orientations and information.

The municipality of Horizonte in Ceará reproduced 1,000 copies and made them available to home care teams, basic healthcare units and the hospitals in the municipality. It is suggested, for future studies, that the applicability of the booklet is followed up in regard to the following indicators: frequency of hospitalizations, respiratory infections, and injury by pressure, among others. In this way, it would be possible to verify the effectiveness of the material among the target demographic.

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