



Validation of a technology for self-care of family caregivers of cancer patients in home-based palliative care

Validação de tecnologia para autocuidado do familiar cuidador de pacientes oncológicos paliativos domiciliares

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Objective: to validate the content of a booklet to subsidize the self-care of family caregivers of cancer patients in home-based palliative care. **Methods:** this is a methodological study. The participants were 11 expert judges. This study was aided by a questionnaire organized according to a Likert scale with items distributed in objectives, structure, presentation and relevance. The quantitative verification of the results was based on a descriptive statistical analysis. **Results:** validation was based on the analysis of the judges, reaching a higher parameter than the one proposed (0.78) for the content validity index; the 21 items surpassed the value of 80.0%. **Conclusion:** it is considered that the booklet is validated and can promote self-care of caregivers of cancer patients in the home setting.

Descriptors: Oncology Nursing; Caregivers; Validation Studies; Educational Technology; Health Education.

Objetivo: validar o conteúdo de uma cartilha para subsidiar o autocuidado de familiares cuidadores de pacientes em cuidados paliativos oncológicos domiciliares. **Métodos:** estudo de caráter metodológico. Os participantes foram 11 juízes especialistas. Estudo auxiliado por um questionário organizado conforme a escala *Likert* com itens distribuídos em objetivos, estrutura, apresentação e relevância. A verificação quantitativa dos resultados pautou-se na análise estatística descritiva. **Resultados:** a validação foi efetivada segundo análise dos juízes, obtendo parâmetro maior que o proposto (0,78) para o índice de validade de conteúdo; os 21 itens ultrapassaram o valor de 80,0%. **Conclusão:** considera-se que a cartilha está validada e pode promover o autocuidado de cuidadores de adoecidos pelo câncer no domicílio.

Descritores: Enfermagem Oncológica; Cuidadores; Estudos de Validação; Tecnologia Educacional; Educação em Saúde.

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Introduction

Cancer has become a worldwide public health problem and more and more patients have been referred to Palliative Care, requiring a new way of care based on improving the quality of life through early identification, correct assessment, treatment of pain and other physical, psychosocial or spiritual problems of the sick people and their families who face challenges associated with life-threatening diseases⁽¹⁾.

When this type of care takes place in the home, the image of a family caregiver emerges. This caregiver faces constant challenges and does not receive the necessary attention from professionals of the current health system to promote their self-care, but rather focus on the needs of the patients. Previous studies have shown that caregivers experience psychic distress, relationship breakdowns, deteriorating well-being, and even a higher incidence of heart diseases. Despite all this, caregivers are largely ignored by support services. Therefore, care models are needed to support them in their caregiving role through stimulation of self-care⁽²⁻³⁾.

For this, caregivers need to carry out activities aimed at maintaining life, health and well-being and to continue the functioning of the body, improving health. Nursing practices need to turn to this possibility⁽⁴⁾. In this way, technology has the potential to provide unprecedented support to caregivers of people living with cancer⁽⁵⁾.

Therefore, nursing can use these technologies as tools to provide, accelerate, and improve the process of health education for self-care. Resources such as the creation of educational booklets bring more understanding and possibilities to assist in the daily construction of new knowledge⁽⁶⁾.

The use of educational technologies also allows a higher quality of the teaching-learning process and communication, intensifying the guidelines passed by professionals. Studies have shown the efficiency of the use of educational booklets, affirming that this type of instrument is capable of promoting positive changes

for knowledge acquisition, helping in the process of adaptation to chronic incurable disease⁽⁷⁾.

Thus, in light of the above, the following questions stand out in the reflection about educational technologies: is a booklet a valid technological tool to foster self-care actions of family caregivers of patients under home-based palliative care for cancer in the context? What would be the possible comments of judges about the material?

Therefore, the study aimed to validate the content of a booklet to subsidize the self-care of family caregivers of patients under palliative care for cancer.

Methods

This is a methodological study whose purpose is to validate and evaluate the content of an instrument. Content validation is a process that accurately examines a given instrument or an inference based on established scores⁽⁸⁾. The construction of the booklet was based on the theory of self-care in universal requirements and supported on the theoretical reference of studies previously carried out by other authors⁽⁹⁾.

The 11 expert judges participating in the study were selected according to the adapted model⁽¹⁰⁾, with the search for information in their curricula through the Lattes platform. Regarding the number of judges in the study, it should be emphasized that the number of specialists may vary, and the study already conducted was used as reference⁽¹¹⁾. The judges consisted of five nurses, one physician, one occupational therapist, one psychologist, one licensee in the Portuguese language, one graphic designer, and one social communicator.

The following criteria were established for selection of judges in the health area: time of at least two years of experience in oncology or palliative care; professional qualification; scientific production; participation in events. For judges from other areas, criteria were: minimum time of two years of experience in their area of work, qualification and productions. Judges who met at least two criteria were included.

The information was collected from April to June 2018. The judges were invited through an invitation letter sent by e-mail. After completing the Informed Consent Term, they received the Evaluation Questionnaire created by the researchers and the Booklet. A period of fifteen days was established for the return of the instruments. If there was no return within this time interval, a new contact would be made, granting another 15 days for return. Of the 11 judges contacted who agreed to participate in the survey, only one had to be replaced.

In the face and content validation, the answers were analyzed according to three aspects: clarity and comprehension of texts and illustrations; relevance; and degree of relevance of the content of the booklet. When deemed necessary, the experts suggested changes, which were considered in the final version.

The evaluation of the original version was done by means of a data collection instrument in the form of a questionnaire according to a Likert scale with items containing questions corresponding to the evaluation of the booklet regarding objectives that refer to the purposes, goals or ends that are to be achieved with the use of the Educational Technology (ET); relevance and structure, that is, how the guidelines are explained; and presentation, which refers to the characteristics that evaluate the degree of significance of the educational material presented. The scores varied from one to four, corresponding to Totally Adequate (TA), Adequate (A), Partially Adequate (PA), and Inadequate (I). The evaluators were also responsible for describing their opinions on the items. After this, the original version continued to be adequate according to the indication of the judges.

The Content Validity Index (CVI) was used to measure the content validity ratio, calculated by dividing the number of judges who assessed the items as appropriate by the total number of judges (evaluation per item), resulting in the proportion of judges who judged the item. This method uses a Likert scale to evaluate the relevance/representativeness of the items. Thus, a minimum index of 0.78 was considered

valid, and for the global CVI, all CVIs that were treated separately were summed and divided by the number of items⁽¹²⁾.

Thus, the quantitative analysis of the results was based on a descriptive statistical analysis, subsidized by the Content Validity Index that measures the proportion of judges who agree on a particular aspect of the instrument. After data collection, the data was tabulated and inserted in a Microsoft Excel® version 2016 worksheet for later statistical analysis.

According to the ethical-legal precepts, the research complied with the norms of Resolution 466/12 and was approved by the Research Ethics Committee of the Ophir Loyola Hospital under Opinion nº 2,521,798.

Results

Among the 11 specialist judges who participated in the study, three were 22 to 30 years old, five were between 31 and 40 years old, and two were between 41 and 50 years old, leading to an average of approximately 35 years. In addition, seven judges were specialists and two were masters. It should be noted that six judges had less than 10 years of experience in oncology/palliative care in their area of practice, and the others (four) had 11 to 15 years of experience, resulting in an average of 11 years of experience.

The first group called "Expert Judges of Other Areas" was made by the face and content evaluation with regard to organization, language, graphics, diagramming, visual communication; judgment of art as expressive language and form of knowledge; and the layout (outline) of the information. A professional licensed in Portuguese language, a graphic designer, and a social communicator were selected to compose this group.

The second group, "Expert Judges of the Health Area", was responsible for judging the specific and thematic content of the booklet to be representative in the desired context. This group was composed of eight judges, namely, five nurses, one physician, one

occupational therapist, and one psychologist.

In relation to the validation of the content of the Educational Technology, the agreement among judges was verified. The assigned 146 (63.2%) responses as TA and 66 (28.6%) as A, resulting in an agreement value greater than 0.78 in each item, reaching 0.91 in the global CVI, which is considered an excellence value. It

can be inferred, therefore, that there was no significant explanation for the invalidity of this technology, because none of the 21 items had lower CVI than the one proposed. Table 1 presents the judgment of the experts in each question evaluated according to Objectives, Structure, Presentation and Relevance, showing the answers considered valid.

Table 1 – Evaluation of objectives, structure, presentation, and relevance by judges, and percentage of agreement obtained through the Content Validity Index

Itens	Scores (n = 11)				CVI	Global CVI
	TA	A	PA	I		
Objective						
1.1 The information/contents are consistent with the daily needs of family caregivers of the Educational Technology	9	0	2	0	0.81	
1.2 The information/contents are important for the quality of self-care of family members of the Educational Technology	10	1	0	0	1	
1.3 It invites and/or instigates behavioral changes and attitudes of family caregivers in their households	8	3	0	0	1	
1.4 It can circulate in the scientific community of the area	9	2	0	0	1	
1.5 The Educational Technology meets the objectives of institutions that offer home-based care service	7	3	0	1	0.90	
Subtotal	43	9	2	1		
Structure and presentation						
2.1 The booklet is appropriate for family caregivers	5	5	1	0	0.90	
2.2 The messages are presented in a clear and objective way	8	2	1	0	0.90	
2.3 The information presented is scientifically correct	8	2	1	0	0.90	
2.4 The material is appropriate to the socio-cultural level of family caregivers of patients in home-based palliative care for cancer	4	6	1	0	0.90	
2.5 There is a logical sequence in the proposed content	7	4	0	0	1	0,91
2.6 The information is well structured in terms of grammar and spelling	6	3	2	0	0.81	
2.7 The writing style is coherent with the level of knowledge of family caregivers	6	4	1	0	0.90	
2.8 The information in the cover, back cover, summary, acknowledgments, and/or presentation are consistent	7	3	1	0	0.90	
2.9 The size of the title and topics is adequate	7	3	1	0	0.90	
2.10 The illustrations are expressive and sufficient	6	4	0	1	0.90	
2.11 The material (paper/print) is appropriate	6	4	1	0	0.90	
Subtotal	70	40	10	1		
Relevance						
3.1 The themes portray aspects that need to be reinforced	8	3	0	0	1	
3.2 The material allows the transfer and generalization of the learning to different contexts, intertwining them with the daily life of caregivers	6	4	1	0	0.90	
3.3 The booklet proposes the construction of innovative knowledge	7	4	0	0	1	
3.4 The material addresses the subjects necessary for the knowledge of family caregivers in the home context	8	1	2	0	0.81	
3.5 The booklet is suitable for use by any family caregiver in the home context	4	6	1	0	0.90	
Subtotal	33	18	4	0		

Totally Adequate: TA; Adequate: A; Partially Adequate: PA; Inadequate: I

The adjusted version of the booklet was entitled “Learning how to better care for yourself” and ended with a language that is within perspectives that promoted self-care among caregivers, helping them to perceive themselves in their new context, providing guidance on the universal needs of self-care, presenting them in simple titles, highlighting positive actions, stimulating and explaining how to sleep better; the need to feed and drink water, perform physical activity, have leisure time to take care of the mind, and ask for help.

The information was written in the form of conversation, as it sounds more natural and facilitates the reading and understanding, with analogies that are familiar to the public. Illustrations of good quality and high definition, designed by a graphic design professional, were used to help to explain/emphasize the ideas, placed close to the texts to which they refer. Regarding layout and design, colors were used with caution to avoid saturation in terms of color, leaving the material visually polluted, and the fonts used in titles were larger than those of the text. The ideas were presented on one page or on both sides of the sheet, so that the reader did not have to flip through the page so as not to forget the first part.

Discussion

The possible limitation of the study was the lack of participation of caregivers in the validation process, since their view on an instrument that will be used by them would further promote the validity of this technology. Another limitation was the few works on the theme available in the databases to expand the discussion. It is believed that the use of this technology will facilitate the coherence of the guidelines passed by the team, besides awakening in individuals a new look regarding their own needs.

Thus, the idealization of a technology focused on care guidelines that can be used by nurses is fundamental to promote the health of caregivers. The tool provides guidance to professionals working in the

area of palliative care. Health and nursing technologies have shown evident advances in care, subsidizing the direct improvement of the provision of assistance for those to whom care is directed, promoting quality of life and adoption of healthy habits, and greater understanding so as to promote faster necessary changes in self-care practices⁽¹³⁾.

As the survival of cancer patients has improved, more time will be spent in performing this care, particularly intensified in the home setting. This is additionally endorsed by sociodemographic and cultural changes, aging of the population reflected in the family environment, since they are more distanced. Therefore, more than ever, the provision of innovative solutions that respond to these new challenges is sorely needed, as well as to assist family members who care for cancer patients in the home setting. There is agreement with respect to the fact that caring for a person with cancer can negatively impact the quality of life, and family caregivers are more likely to experience physical, social and emotional distress compared to non-caregivers⁽¹⁴⁾.

It is important to note that, in the cancer scenario, family caregivers have to provide multifaceted health care. They administer medication, control the symptoms, the exercise and mobility, but they do not have the necessary equipment, skills and confidence to perform complex tasks. Another problematic point is when family caregivers feel overwhelmed by the lack of time to take care of their own physical and mental health, which may adversely affect the patient’s health outcomes. A basis in the literature is necessary to support caregivers’ interventions with the potential of improving their quality of life, emotional well-being, and suffering. However, this basis also stands out as a gap in the field⁽¹⁴⁾.

From this point of view, the booklet “Learning how to better care for yourself”, which obtained high indices in the validation process, demonstrates the great importance attributed by the judges to approaching emotional/psychological and social aspects that can influence the reduction of overload. The relevance

attested in this study is in agreement with other studies that also validated materials, such as in the instrument for nursing consultations to pregnant women with diabetes mellitus, in which the CVI ranged from 0.80 to 1⁽¹⁵⁾. On the other hand, the booklet on excess weight for adults with hypertension was evaluated with a global CVI of 0.78⁽¹⁶⁾ and another study carried out in China obtained indices varying from 0.71 to 1, with a validity of 0.78⁽¹⁷⁾. These latter results are low in comparison to those presented in the present study. The participation of several professionals in the content validation process is a favorable aspect, since it allows merging innumerable specific sets of knowledge related to palliative care addressed through a technology, which is scarce in the scientific environment. Similarly, as in other research, it was possible to finalize the material in order to present it as multiprofessional and coherent instrument⁽¹⁸⁾.

Still in relation to the relevance of the technology produced in this research, a review concluded that there is currently a shortage of scientific evidence, mediated or not by technologies, aimed at helping family caregivers of cancer patients, as well as a homogeneous approach to improve usability and adoption of the interventions developed. Thus, before the population growth and the increased costs of advanced cancer therapies, interventions supported by technologies have the potential to provide effective solutions for families facing difficulties related to cancer⁽¹⁴⁾.

Educational technologies consider the transformations occurring with subjects, in this case family caregivers, and have the capacity to provide information that is more meaningful, as it is based on their real needs, brought about by their new condition as caregivers, thus promoting adherence and change. This is corroborated by a study that pointed out family caregivers of cancer patients as users of technologies, being receptive to their use, while also recognizing the benefits of using such tools to reduce their overload. The study also indicated that regardless of the age or level of burden, caregivers have used technologies. The combination of an active technology and perceived

incentives for its use provides support for the development of evidence-based interventions to reduce caregiver overload⁽¹⁹⁾.

Therefore, the booklet is relevant because it presents as a differential trait the focus of health education aimed at family caregivers to promote their own self-care, expanding the line of care of oncological palliative care. The literature points out that the focus of this care is on the sick person, which corroborates the need for validating a technology aimed at palliative care, as pointed out⁽²⁰⁾, because despite the expansion of technology validation studies in the literature, very few studies have specifically addressed palliative care or cancer.

In view of this, the technology proposed in this work not only broadens the discussion within the theme, but also meets the recommendations given in a research⁽¹⁹⁾ that sustained that a technology-based intervention that supports caregivers of cancer patients in a way to meet their needs by enabling them to maintain or improve their quality of life and relieve their burden could be developed and widely used.

In this way, technology becomes important in the health education process and nurses can rely on information resources to facilitate communication and understanding among the participants⁽¹³⁾.

In conclusion, it should be emphasized that health education made possible through the booklet "Learning how to better care for yourself" make caregivers to be seen as subjects, as well as collaborators in palliative care, giving them the necessary support from the team to develop care for other person and for themselves. To this end, it is fundamental that professionals, especially nurses, continue to investigate the anxieties and fragilities of these actors among other aspects, seeking to understand the difficulties faced on a daily basis⁽¹⁵⁾.

Conclusion

The booklet was recognized as valid to subsidize the self-care of caregivers in the home setting,

according to expert judges, since their agreement exceeded the proposed Content Validity Index. It is considered that the booklet is validated and can promote self-care of caregivers of cancer patients in the home context.

Collaborations

Vale JMM contributed in the design, analysis and interpretation of data. Marques Neto AC and Mendes CP contributed in the writing of the article and relevant critical review of the intellectual content. Santana ME contributed in the final approval of the version to be published.

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