

“(Surviving) Breast Cancer”: Development and Validation of an Educational Booklet for Women Survivors of Breast Cancer

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“(Sobre)viver ao Câncer de Mama”: Construção e Validação de uma Cartilha Educativa para Mulheres Sobreviventes do Câncer de Mama
“(Sobre)vivir al Câncer de Mama”: Desarrollo y Validación de un Folleto Educativo para Mujeres Supervivientes de Câncer de Mama

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ABSTRACT

Introduction: Breast cancer is frequent and a major cause of morbidity and mortality; survivors face physical, psychological, and financial challenges, requiring education for post-treatment self-care. **Objective:** To develop and validate an educational booklet aimed at women who have survived breast cancer, focusing on promoting self-care and improving quality of life. **Method:** A methodological study conducted between March and October 2025 in three stages: 1) situational diagnosis and literature review; 2) booklet development; 3) content and face validation. Data analysis was performed using Content and Face Validity Indices. **Results:** The themes that comprised the booklet emerged from the situational diagnosis, namely: chronic pain after surgery, self-image, healthy eating, physical activity, hair care after treatment, skin care, and resumption of sexual life. Thirteen nurses participated in the content validation, and the Content Validity Index ranged from 0.85 to 1.0. Eleven nurses validated the appearance, and the Appearance Validity Index ranged between 0.64 (minimum) and 1.0 (maximum). **Conclusion:** The booklet is a methodologically consistent and potentially applicable educational technology for monitoring women who have survived breast cancer in the post-treatment period.

Key words: Cancer Survivors; Breast Neoplasms; Teaching Materials; Patient Education as Topic; Quality of Life.

RESUMO

Introdução: O câncer de mama é frequente e grande causa de morbimortalidade; sobreviventes enfrentam desafios físicos, psicológicos e financeiros, exigindo educação para autocuidado pós-tratamento. **Objetivo:** Elaborar e validar uma cartilha educativa direcionada a mulheres sobreviventes de câncer de mama, com foco na promoção do autocuidado e na melhoria da qualidade de vida. **Método:** Estudo metodológico conduzido entre março e outubro de 2025, em três etapas: 1) diagnóstico situacional e revisão da literatura; 2) elaboração da cartilha; 3) validação de conteúdo e aparência. A análise dos dados ocorreu pelos Índices de Validade de Conteúdo e Aparência. **Resultados:** Do diagnóstico situacional, surgiram os temas que compuseram a cartilha, a saber: dor crônica após a cirurgia, autoimagem, alimentação saudável, atividade física, cuidado com o cabelo após o tratamento, cuidados com a pele e retomada da vida sexual. Participaram da validação de conteúdo 13 enfermeiros e o Índice de Validade de Conteúdo variou entre 0,85 e 1,0. Validaram a aparência 11 enfermeiros, e o Índice de Validade de Aparência mínimo foi de 0,64 a máximo 1,0. **Conclusão:** A cartilha configura-se como tecnologia educativa metodologicamente consistente e potencialmente aplicável no acompanhamento de mulheres sobreviventes de câncer de mama no período pós-tratamento.

Palavras-chave: Sobreviventes de Câncer; Neoplasias da Mama; Materiais de Ensino; Educação do Paciente; Qualidade de Vida.

RESUMEN

Introducción: El cáncer de mama es frecuente y una gran causa de morbimortalidad; los sobrevivientes enfrentan desafíos físicos, psicológicos y económicos, lo que exige educación para el autocuidado postratamiento. **Objetivo:** Elaborar y validar un folleto educativo dirigido a mujeres sobrevivientes de cáncer de mama, con enfoque en la promoción del autocuidado y la mejora de la calidad de vida. **Método:** Estudio metodológico realizado entre marzo y octubre de 2025, en tres etapas: 1) diagnóstico situacional y revisión de la literatura; 2) elaboración del folleto; 3) validación de contenido y apariencia. Se realizó el análisis de los datos mediante los Índices de Validez de Contenido y Apariencia. **Resultados:** Con base en el diagnóstico situacional surgieron los temas que compusieron el folleto, a saber: dolor crónico después de la cirugía, autoimagen, alimentación saludable, actividad física, cuidado del cabello después del tratamiento, cuidados con la piel y reanudación de la vida sexual. Participaron de la validación de contenido 13 enfermeros y el Índice de Validez de Contenido varió entre 0,85 y 1,0. Validaron la apariencia 11 enfermeros, y el Índice de Validez de Apariencia mínimo fue de 0,64 y máximo de 1,0. **Conclusión:** El folleto se configura como una tecnología educativa metodológicamente consistente y potencialmente aplicable en el seguimiento de mujeres sobrevivientes de cáncer de mama en el período postratamiento.

Palabras clave: Supervivientes de Câncer; Neoplasias de la Mama; Materiales de Enseñanza; Educación del Paciente como Asunto; Calidad de Vida.

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INTRODUCTION

Breast cancer is the malignant neoplasm most frequently diagnosed today in women in the whole world, continuing to be one of the main causes of female morbimortality¹. Recent global estimates indicate high incidence and significant impact on health systems, consolidating the disease as priority in the international agenda of cancer control¹.

In Brazil, the scenario follows the world tendency. For the triennium 2026-2028, the National Cancer Institute (INCA) estimates close to 781 thousand new cases of cancer annually, being breast cancer responsible for 30% of these figures². These data reinforce the magnitude of the problem and necessity of organization of care networks that are able to address not only the treatment, but also the longitudinal follow-up of these women².

In parallel to the high incidence, advances in screening, early diagnosis and oncologic therapies have promoted a significant increase of survival³. It is estimated that nearly 7.8 million women in the world have survived at least for five years after the diagnosis of breast cancer³. The growth of the population of survivors shifts the exclusively curative focus towards an extended approach of cancer survival⁴.

The concept of survival comprehends the whole period from the time of diagnosis and extending through the lifetime, including monitoring of recurrence, management of late effects and attention to the psychosocial dimensions of the disease⁴. Evidences indicate that women survivors frequently experience the fear of recurrence, self-image changes, sexual dysfunctions, persistent fatigue and chronic pain, repercussions that directly impact the quality of life⁵.

Further to clinical manifestations, a recent study demonstrated that cancer survivors can face financial toxicity arising from direct and indirect treatment costs, loss of income and occupational impact, a condition associated with worse psychosocial outcome⁶.

Although international guidelines recommend periodic follow-up post treatment⁷, investigations indicate that doubts related to self-care and rehabilitation persist in the post-treatment period⁸.

In this context, health education plays a strategic role in the promotion of autonomy and strengthening of care⁹. Educational technologies as booklets are acknowledged as tools able to translate scientific evidences in accessible language, contributing to expand the knowledge, adherence to healthy practices and strengthening of the bond among professionals and users⁹.

Within the scope of Brazilian public policies, educational materials for breast cancer have been developed targeted to prevention and integral care¹⁰.

Among the educational resources available in the Brazilian context, the booklet "Breast cancer: let's talk about it?" elaborated by INCA and the document titled "Full care to the person with breast cancer: guidelines for professionals of Primary Health Care" published by the Ministry of Health stand out. These materials reinforce the importance of health education within the care to women with breast cancer. However, the expansion of educational strategies focused specifically to the demands of survivors in the post-treatment period⁹⁻¹¹ continues to be a necessity.

In view of the growth of the survivors population and the complexity of physical and psychosocial demands during post-treatment, this study is aimed at elaborating and validating an educational booklet targeted to women survivors of breast cancer with emphasis on the promotion of self-care and improvement of the quality of life.

METHOD

Methodological study developed at a public university in Southern Brazil between March and October 2025 in three stages: 1) situational diagnosis and literature review; 2) elaboration of the booklet; 3) content and appearance validity.

The first stage consisted of the situational diagnosis to identify priority themes for the elaboration of the educational booklet for women survivors of breast cancer.

Nurses of the nursing team of a hematology and oncology outpatient unit of a teaching hospital located in Southern Brazil participated of this stage. The inclusion criteria were nurses or licensed practical nurses working in oncology for at least six months, exclusion criteria have not been determined.

Two in-person meetings were conducted in April 2025 in different times to allow the participation of a large number of professionals of the morning and afternoon shifts. The meetings were held at the meeting room of the unit and were coordinated by the investigators after the presentation of the objectives and clarifications about the participation in the study. One of the participating nurses is a breast cancer survivor.

The discussion was conducted based on the following research question: "What are the main doubts and necessities brought up by women survivors of breast cancer after the end of the treatment?"

The contributions of the participants were registered by the investigators and later organized according to frequency and pertinence to the objective of the study. The themes most frequently brought up underpinned the elaboration of the educational booklet.

Next, in order to scientifically support the elaboration of the booklet, a literature search was conducted in May

2025 in the PubMed, Scopus, Web of Science, CINAHL and Virtual Health Library (VHL) databases.

Each theme identified in the situational diagnosis was investigated independently such as pain, self-image, food, physical activity and sexual activity utilizing the descriptors related to the theme and breast cancer.

The studies were analyzed in terms of relevance and applicability for the construction of the educational booklet, being utilized to strengthen the guidelines presented in the educational material.

The elaboration of the booklet followed a process structured in three main stages: (1) construction of the text, (2) search and selection of illustrations and (3) final review. The first phase prioritized the objective and accessible language, considering the different levels of education of the target-audience to make the material understandable but preserving the quality of the information disclosed. Icons, colors and illustrations were utilized to reinforce the contents and facilitate reading and assimilation.

The platform Canva®, version Pro was utilized which ensured access to graphic resources, illustrative figures and layout tools to improve the appearance and visual organization of the material.

The validity of the content and appearance was made by oncology experienced nurses who were approached in the group of studies about quality of life in oncology and provided clarifications on the study goals and form of participation. The inclusion criteria were having Master degree or PhD, and experience in oncology. There were no exclusion criteria. The participation consisted of evaluating the booklet and filling up three instruments: 1) Qualification of the experts; 2) Content Validity Index in Health (CVI); 3) Appearance Validity Index of Educational Health Technology (AVI).

The 13 experts enrolled received the booklet and evaluation instruments electronically through the platform Google Forms®. All the participants responded to the CVI and signed the Informed Consent Form, however, two experts did not complete the AVI and the demographic questionnaire, therefore, 13 experts evaluated the content and 11 evaluated the appearance.

A 5-point Likert scale¹² was utilized to evaluate the items of the instruments. In addition to the objective questions, the experts were free to add suggestions and comments on content, language, organization and appearance of the booklet for potential adjustments. The validation was completed in a single round of evaluation, the Delphi method was not applied.

The data obtained from the validation instruments were inserted and analyzed in Microsoft Excel® electronic charts. Both instruments were calculated and reached

positive results such as 4 or 5 according to the experts. Items with CVI ≥ 0.78 and CVI total ≥ 0.90 were valid according to the standard, CVI ≥ 0.78 , excellent, between 0.60 and 0.77, good and < 0.59 , poor¹³. For the calculation of AVI, > 0.78 is excellent, between 0.60 and 0.77, needs adjustment to improve the appearance of the educational health technology and < 0.60 is classified as poor and the key-point of the material must be revised.

The Ethics Committee of the “Complexo Hospital de Clínicas da Universidade Federal do Paraná” approved the study, report number 7,464,117 (CAAE (submission for ethical review): 80508224.5.0000.0096) in compliance with Directive 466/2012 of the National Health Council for studies involving human beings.

RESULTS

Seven female nurses (87.5%) – three (37.5%) had Master degree, four (50%) were specialized – and one licensed practical nurse participated of the situational diagnosis, all of them worked for more than three years at the unit. The themes most frequently mentioned by the nursing team of the hematology and oncology outpatient unit were: physical activity, food, sexuality, self-image, alopecia, chronic pain and mastectomy. These topics reflected the main demands of women survivors of breast cancer as priority areas for educational intervention and support perceived by the professionals.

Based on the literature review, the investigators gathered information and organized the booklet in seven core topics. For each topic, a survey of the scientific literature was conducted to identify the most adequate approaches for the problems presented that were described objectively and in accessible language.

The content was elaborated considering the target-audience formed by women survivors of breast cancer that guided both the language and the selection of images. In addition, different tones of the color rose were selected to associate with the campaign “Outubro Rosa”, strengthening the visual identity of the material and the relation with the theme. The contents of the booklet were organized in seven topics described in Chart 1.

13 nurses participated of the content validity and 11, of the appearance validity, being six women, four doctors and eight aged 31-39 years according to Figure 1.

Table 1 presents the results of the content validity of the booklet. All the items validated presented Content Validity Index ranging from 0.85 to 1.0, total CVI of 0.98. No adjustments post content validity were made.

Table 2 presents the Appearance Validity Index of each item evaluated. Most of the items presented excellent indexes. The lowest AVI was found in item 5, forms of the

Chart 1. Topics for the booklet “(Surviving) breast cancer”. Curitiba, PR, Brazil, 2025

Content	Description
1. Post-surgery chronic pain	Characteristics of the pain, when asking for help, how to alleviate pain
2. Self-image	Emphasizing recommended care for mastectomized women, strategies to improve self-image, rights related to breast reconstruction
3. Healthy eating	Nutritional recommendations targeted to recovery, food to be avoided
4. Physical activity	Emphasizing regular practice of exercises, barriers and important considerations, tips of free physical activity classes
5. Hair care post treatment	Guidelines about hair growth, options of cosmetics
6. Skincare	Sunblock, tatoos, bath
7. Resumption of sexual life	Use of lubes, reclaiming self-esteem

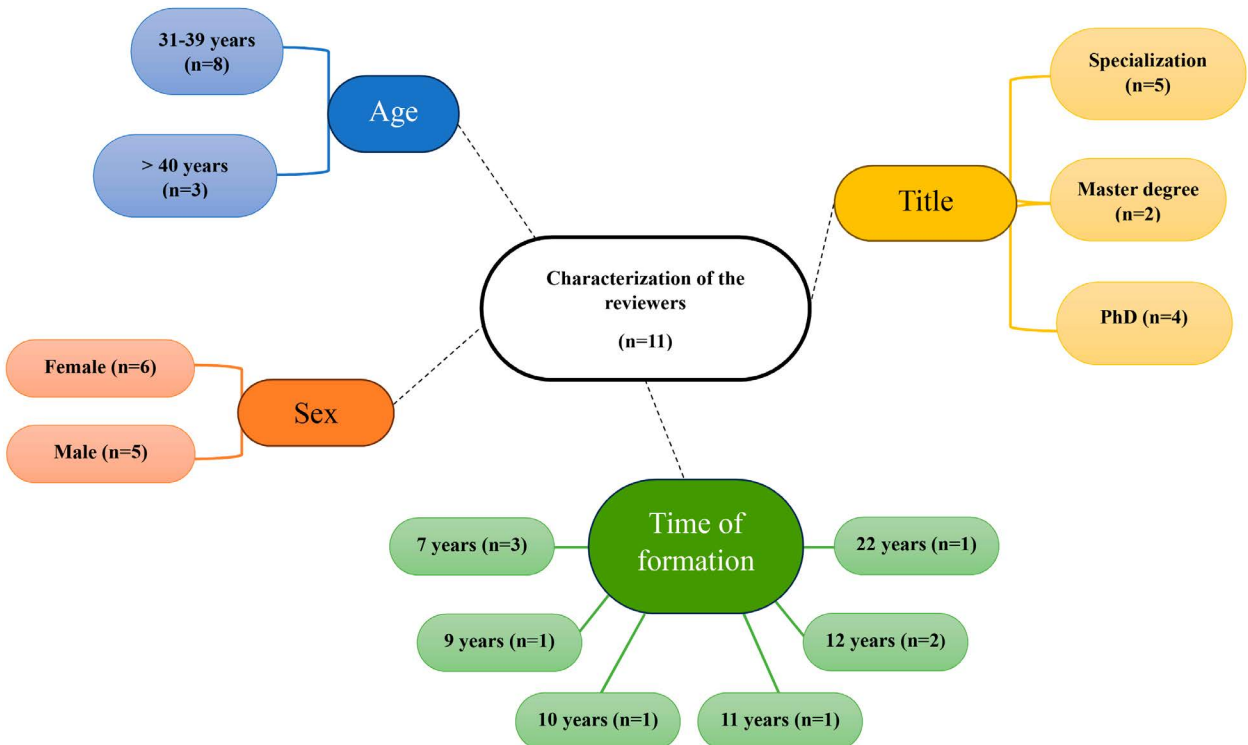


Figure 1. Characterization of the participants of the appearance validity. Curitiba, PR, Brazil, 2025

illustrations (AVI=0.64), a rate requiring adjustments to the criteria adopted. However, the suggestions of the experts were reviewed by the research team and deemed insufficient to warrant substantial modifications in the illustrations since the global index was excellent (AVI total=0.84).

The booklet was turned into a scannable code to facilitate the access by health professionals and patients (Figure 2).

DISCUSSION

This study elaborated and validated an educational booklet for women survivors of breast cancer with emphasis on the post-treatment period, considering that this is a period of doubts and few medical visits.

The booklet’s themes were based on the demands identified by the nursing team in the situational diagnosis who pointed out the recurring topics of the post-treatment follow-up: post-surgery persistent pain, self-image alterations, doubts about food and physical activity, in addition to practical guidelines on hair and skin care and sexuality¹¹. Said dimensions reflect the necessities widely described in the literature on breast cancer survival that acknowledges the concomitant presence of persistent physical repercussions, body changes and challenges of daily self-care as part of the post-therapy period^{15,16}.

Post-surgery chronic pain is among the most frequently reported clinical manifestations with relevant functional impact. A recent systematic review described that the significant prevalence of post-mastectomy pain

Table 1. Results of the Content Validity Index in Educational Health. Curitiba, PR, Brazil, 2025

Content Validity Instrument in Educational Health	
Items	CVI-I
Objectives: Purpose, Goals or Finalities	
1. Addresses the theme proposed	1
2. Appropriate for the teaching-learning process	1
3. Clarifies doubts about the theme addressed	1
4. Stimulates reflection on the theme	1
5. Stimulates behavior change	1
Structure/Presentation: Organization, Structure, Strategy, Coherence and Sufficiency	
6. The language is appropriate to the target-audience	1
7. The language is appropriate to the educational material	1
8. Interactive language allowing the active involvement in the educational process	1
9. Correct information	1
10. Objective information	1
11. Enlightening information	1
12. Necessary information	1
13. Logical sequence of ideas	0.92
14. Current theme	1
15. Appropriate size of the text	0.92
Relevance: Significance, Impact, Motivation and Interest	
16. Stimulates learning	1
17. Contributes to the knowledge in the area	1
18. Stimulates interest for the theme	1
19. Suggestions to improve the content of the booklet	0.85
CVI total	0.98

Caption: CVI = Content Validity Index.

syndrome and its potential neuropathic characteristics can interfere in the activities of professional evaluation^{15,16}.

Further to the physical manifestations, the treatment-related body repercussions are also part of the backbone of the healthcare. Post-mastectomy self-image influences self-esteem, interpersonal relations and psychosocial adaptation⁷. In the Brazilian context, breast reconstruction is warranted by the National Health System (SUS) in compliance with Law number 12,802/2013¹⁷, extended by Law number 13,770/2018¹⁸, that ensures the reconstructive surgery in the same surgical procedure or immediately when clinical conditions permit¹⁶. Recent studies indicate that interventions related to body image and reconstruction can entail positive repercussions on the quality of life and resignification of the experience of becoming ill¹⁶.

Table 2. Results of the appearance validity instrument of educational health technology. Curitiba, PR, Brazil, 2025

Appearance Validity Instrument of Educational Health Technology	
Items	AVI
1. Illustrations are appropriate to the target-audience	0.82
2. Illustrations are clear and comprehensible	0.73
3. Illustrations are relevant for the target-audience to understand the content	0.73
4. The colors of the illustrations are appropriate for the type of material	0.91
5. The forms of the illustrations are appropriate for the type of material	0.64
6. The illustrations portray the daily life of the target-audience (intervention)	0.82
7. The figures are harmonically displayed in the text	1
8. The figures elucidate the content of the educational material	1
9. The illustrations help the presentation of the theme and follow a logic sequence	1
10. The quantity of illustrations is appropriate to the educational material	0.82
11. The size of the illustrations is appropriate to the educational material	0.91
12. The illustrations help to change the behavior and attitudes of the target-audience	0.73
AVI total	0.84

Captions: AVI = Appearance Validity Instrument.



Figure 2. QR Code for the booklet “(Surviving) breast cancer”. Curitiba, PR, Brazil, 2025

Still in the setting of psychosocial dimensions, the resumption of sexual life is frequently described as a post-treatment challenge. Hormonal shifts, genital discomfort and body struggles can negatively impact the sexual experience, requiring specific guidelines about the use of lubes and strategies to reclaim self-esteem^{7,16}.

Within the scope of health promotion and functional rehabilitation, healthy feeding and physical activity are pillars of the longitudinal care. Brazilian studies demonstrate the high prevalence of overweight among survivors, a condition associated with high symptomatic burden and possible prognostic implications^{9,10}. Recent updates of the NCCN Guidelines® Insights: Survivorship, Version 2.2025 reinforce nutritional counselling and weight control as main features of follow-up¹⁹.

The regular practice of physical activity as a complement is described as safe intervention and associated with the improvement of the quality of life, reduction of fatigue and cardiometabolic benefits¹⁵. The same international document of survivorship emphasizes the incorporation of physical exercise matched to individual conditions as key strategy post-treatment¹⁹.

Skin and hair changes require specific guidelines after the end of the treatment within daily self-care. A recent review study described that chemotherapy-related alopecia is usually reversible with regular growth of strands of hair after the end of the treatment, although temporary alterations of texture and color may occur²⁰. Evidences highlight the importance of delicate scalp care and the choice of least aggressive cosmetics during hair regrowth^{20,21}.

Comparative reviews of international guidelines on skin care converge in regard to least aggressive hygiene products, reduction of friction and preservation of the cutaneous barrier²². The guideline of the Multinational Association of Supportive Care in Cancer (MASCC) systematizes recommendations for prevention and management of treatment-related skin changes²³. In addition, a review study on clinical photoprotection highlights the necessity of structured guideline in regard to the regular use of sunblock and strategies of physical protection²⁴. Contemporary studies discuss alternatives to permanent skin marks in breast radiotherapy in view of esthetic and psychosocial implications^{25,26}.

The appropriateness of this content is reinforced by Brazilian and international normative documents. The document “*Cuidado integral da pessoa com câncer de mama: orientações para profissionais da Atenção Primária à Saúde*”, of the Brazilian Ministry of Health¹⁰ and the INCA's booklet “*Câncer de mama: vamos falar sobre isso?*”⁹, acknowledge the importance of health education and longitudinal follow-up. However, these materials are primarily focused to diagnosis and therapeutic with least specific systematization for the period of late survival. International guidelines such as the NCCN Guidelines® Insights: Survivorship recommend healthcare structured plans, reinforcing the necessity of educational technologies that instrumentalize these guidelines into healthcare practice¹⁹.

The systematic and dependable organization of the recommendations required a thorough methodological evaluation. The literature recommends the use of the Content Validity Index (CVI) in educational technologies and instruments as a parameter for the analysis of the representativeness and clarity of the items¹³. Methodological studies of validity of instruments for cancer survival, such as the translation and validation of the healthcare plan for breast cancer survivors, demonstrate that structured processes with experts contribute for thematic consistency and clinical applicability²⁷. The high validity indexes obtained in the present study reinforce the methodological robustness of the booklet developed²⁷.

While integrating scientific evidences, normative backbone and actual healthcare demands, the booklet is an educational technology potentially able to qualify the outpatient segment and strengthen post-treatment self-care¹⁷.

The study limitations should be considered in the interpretation of the results. The situational diagnosis was performed in a single specialized outpatient unit, which can limit the generalizability to other contexts. In addition, the validation of the content and of the appearance have been conducted exclusively with nurses and not with women survivors of breast cancer, the target-audience of the educational technology.

Although nurses play a relevant role in longitudinal follow-up of these women, the themes addressed in the booklet encompass aspects related to different areas of health, including nutrition, physical activity, pain management, sexuality and skincare. Future validation steps involving professionals such as nutritionists, physiotherapists, physical educators, pharmacists and physicians can contribute to expand the reach and scientific rigor of the material. Additionally, it is recommended validation studies with the target-audience and evaluation of the efficacy of the booklet in different healthcare scenarios.

CONCLUSION

The booklet “(Surviving) breast cancer” presented satisfactory Content Validity and Appearance Validity Indexes, demonstrating theoretical consistence and pertinence in regard to post-treatment necessities. The educational technology developed is a potentially applicable instrument to follow-up women survivors of breast cancer and can contribute to strengthen self-care and qualification of healthcare guidelines.

However, it is emphasized the necessity of validation by the target-audience and studies that evaluate its effectiveness in different healthcare scenarios, investigating

impacts on the autonomy, adherence to recommendations and psychosocial coping. The consolidation of educational technologies reinforces the commitment of oncology nursing with evidence-based practices and the construction of strategies that acknowledge cancer survival as a singular, complex phase and deserving qualified attention.

CONTRIBUTIONS

Jacqueline Waiara and Vanina Battisti Roberti contributed to the writing and critical review. Luciana de Alcantara Nogueira, Luciana Puchalski Kalinke, Jacqueline Munhões dos Santos Soares, Aramí Herrera Martinez Flecha and Gabriella Maria de Abreu Correa contributed substantially to the study design and conception, acquisition, analysis and interpretation of the data, writing and critical review. The authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTEREST

There is no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

All the content underlying the text is contained in the manuscript.

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