

Care plan for breast cancer survivors: translation and validation

Plano de cuidados para sobreviventes de câncer de mama: tradução e validação
Plan de cuidados para sobreviventes de cáncer de mama: traducción y validación

Maria das Graças Silva Matsubara^{1,2}  <https://orcid.org/0000-0002-9943-6722>

Raquel Esteves Guimarães²  <https://orcid.org/0000-0003-1733-2741>

Fabiana Baroni Makdissi²  <https://orcid.org/0000-0002-4442-0870>

Simone Elias³  <https://orcid.org/0000-0002-9909-0717>

Cristiane Decat Bergerot⁴  <https://orcid.org/0000-0003-0037-0303>

Kimlin Tam Ashing⁴  <https://orcid.org/0000-0002-6209-508X>

Edvane Birelo Lopes De Domenico¹  <https://orcid.org/0000-0001-7455-1727>

How to cite:

Matsubara MG, Guimarães RE, Makdissi FB, Elias S, Bergerot CD, Ashing KT, et al. Care plan for breast cancer survivors: translation and validation. Acta Paul Enferm. 2023;36:eAPE01122.

DOI

<http://dx.doi.org/10.37689/acta-ape/2023A0011222>



Keywords

Breast neoplasms; Cancer survivors; Quality of life; Patient care planning; Validation study; Translations; Surveys and questionnaires

Descritores

Neoplasias da mama; Sobreviventes de câncer; Qualidade de vida; Planejamento de assistência ao paciente; Estudo de validação; Traduções; Inquéritos e questionários

Descriptores

Neoplasias de la mama; Supervivientes de cáncer; Calidad de vida; Planificación de atención al paciente; Estudio de validación; Traducciones; Encuestas y cuestionarios

Submitted

June 17, 2022

Accepted

October 24, 2022

Corresponding author

Maria das Graças Silva Matsubara
E-mail: graca.matsubara@gmail.com

Associate Editor (Peer review process):

Kelly Pereira Coca
(<https://orcid.org/0000-0002-3604-852X>)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil

Abstract

Objective: To translate, cross-culturally adapt and validate the content of the Treatment Summary and Survivorship Care Plan (TSSCP-S) for Brazilian breast cancer survivors.

Methods: Methodological, quantitative study performed according to the steps of translation, compatibility and back-translation, construction of consensus of opinions in a group of experts for content validation, according to the Delphi technique and user evaluation.

Results: The translated and cross-culturally adapted plan was evaluated by ten professionals, including nurses, physicians, psychologists, nutritionists and physical therapists with a degree, scientific production, knowledge and time working on the subject. Consensus was obtained in two rounds. The instrument presented a content validity coefficient of 83.3% in the second round of Delphi. In the evaluation of content, clarity, usefulness, cultural and socioecological responsiveness domains, agreement was 93.3%. The sociodemographic and clinical profile of users was heterogeneous, contributing to the necessary cultural adjustments, with a final consensus of 93.9%.

Conclusion: The care plan was translated into Brazilian Portuguese, cross-culturally adapted and its contents were validated considering national health policies.

Resumo

Objetivo: Traduzir, adaptar transculturalmente e validar o conteúdo do *Treatment Summary and Survivorship Care Plan (TSSCP-S)* para sobreviventes brasileiras de câncer de mama.

Métodos: Estudo metodológico, quantitativo, executado de acordo com as etapas de tradução, compatibilização e retrotradução, construção de consenso de opiniões de um grupo de especialistas para a validação de conteúdo, de acordo com a Técnica Delphi e avaliação do usuário.

Resultados: O plano traduzido e adaptado transculturalmente foi avaliado por 10 profissionais, entre estes, enfermeiros, médicos, psicólogos, nutricionista e fisioterapeuta, possuidores de titulação, produção científica, conhecimento e tempo de atuação na temática e o consenso foi obtido em duas rodadas. O instrumento apresentou coeficiente de validade de conteúdo de 83,3% na segunda rodada da Delphi. Na avaliação dos domínios conteúdo, clareza, utilidade, responsividade cultural e socioecológica, a concordância foi de 93,3%. O perfil sócio demográfico e clínico das usuárias foi heterogêneo, contribuindo para os ajustes culturais necessários, com consenso final de 93,9%.

Conclusão: O plano de cuidados foi traduzido para o português do Brasil, adaptado transculturalmente e seus conteúdos foram validados, considerando as políticas de saúde nacionais.

¹Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

²A. C. Camargo Cancer Center, São Paulo, SP, Brazil.

³Escola Paulista de Medicina, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

⁴City of Hope Comprehensive Cancer Center, Duarte, California, USA.

Conflicts of interest: none to declare.

Resumen

Objetivo: Traducir, adaptar transculturalmente y validar el contenido del *Treatment Summary and Survivorship Care Plan* (TSSCP-S) para sobrevivientes brasileñas de cáncer de mama.

Métodos: Estudio metodológico, cuantitativo, ejecutado de acuerdo con las etapas de traducción, compatibilización y retrotraducción, construcción de consenso de opiniones de un grupo de especialistas para la validación de contenido, de acuerdo con el método Delphi y evaluación del usuario.

Resultados: El plan traducido y adaptado transculturalmente fue evaluado por diez profesionales, entre ellos enfermeros, médicos, psicólogos, nutricionista y fisioterapeuta, con titulación académica, producción científica, conocimiento y tiempo de actuación en la temática, y el consenso se obtuvo en dos rondas. El instrumento presentó un coeficiente de validez de contenido del 83,3 % en la segunda ronda de Delphi. En la evaluación de los dominios contenido, claridad, utilidad, responsividad cultural y socioecológica, la concordancia fue del 93,3 %. El perfil sociodemográfico y clínico de las usuarias fue heterogéneo, lo que contribuye a los ajustes culturales necesarios, con consenso final del 93,9 %.

Conclusión: El plan de cuidados fue traducido al portugués de Brasil, adaptado transculturalmente y sus contenidos fueron validados, considerando las políticas sanitarias nacionales.

Introduction

The incidence of cancer is increasing significantly worldwide, with a projection of 21.6 million patients per year by 2030.⁽¹⁾ In Brazil, 450,000 new cases of cancer (excluding non-melanoma skin cancer) are estimated for the 2020-2022 triennium; breast cancer ranks first among women, with 66,280 cases.⁽²⁾

According to the American Cancer Society (ACS), the five-year survival rate for female patients with breast cancer is currently at 90%.⁽³⁾ The CONCORD III study, an international program for the global surveillance of cancer survival, estimated the five-year survival rate at 75% for breast cancer in Brazil for the 2010-2014 period.⁽¹⁾

The cancer survival term comprises the time of life that begins after diagnosis, and can be acute or prolonged.^(4,5) The first five years after treatment are the period of greater vulnerability, when survivors face several problems, including late symptoms caused by cancer and its treatment.⁽⁶⁾

Considering the diversity of changes that imply physical, emotional and social changes, reflecting in the survivor's daily life, it is essential to act in the control and mitigation of adverse effects, having resources such as an individualized care plan for survival.^(6,7)

Several North American institutions, the Committee of the Institute of Medicine (IOM), the American Commission of Cancer Surgeons of the American College, the National Coalition for Cancer Survivorship (NCCS) and the American Society of Clinical Oncology (ASCO) have engaged

with the Survivors of Cancer theme, with the recommendation to implement the Treatment Summary and Survivorship Care Plan (TSSCP). The TSSCP provides guidelines for survivor care with the aim to improve surveillance and quality of care after acute and health-related treatment. Care planning should include a treatment summary, potential side effects, surveillance guidelines, follow-up care, health warnings, and quality of life (QoL) problems.⁽⁸⁾

Given the relevance of this model, the TSSCP/ASCO was transcreated into Spanish, called the Treatment Summary and Survivorship Care Plan (TSSCP-S), guided by the shared care models of psycho-oncology and the contextual model of QoL, structurally and qualitatively aimed at breast cancer patients from the Latin community residing in the North American society.⁽⁸⁾

Care plans can promote self-management and contribute to the cancer survivor's QoL.⁽⁹⁾ Therefore, considering the benefits of care plans and the fact that in Brazil there are no tested and validated models for this population, the aim of this study was to translate, cross-culturally adapt and validate the contents of the Treatment Summary and Survivorship Care Plan (TSSCP-S) for Brazilian breast cancer survivors.

Methods

This is a methodological study of translation, cross-cultural adaptation and measurement of the content validity of the original version of the Treatment Summary and Survivorship Care Plan -

Spanish (TSSCP-S) in Spanish into Portuguese, carried out in the city of São Paulo, São Paulo, Brazil.

The TSSCP-S comprises information and guidelines for assistance to breast cancer survivors contained in a single document, with the objectives of improving surveillance, quality of care after acute treatment and health-related care. Care planning includes treatment summary, potential side effects, surveillance guidelines, follow-up care, health advice, and QoL issues. The choice for the Spanish version was based on data analysis that indicated the superiority of the TSSCP-S (Spanish) in relation to the TSSCP/ASCO (English) in the domains of content ($p=0.02$), clarity ($p=0,02$), utility ($p=0.04$), cultural and linguistic responsiveness ($p=0.03$) and socioecological responsiveness ($p=0.01$), corroborated after inquiring the main researcher of the TSSCP-S development project, who recommended it and agreed to participate in the design of the current study.⁽⁸⁾

Data collection took place from August 2019 to July 2020. The process of translation and cross-cultural adaptation was based on the methodological framework proposed by Beaton, Bombardier, Guillemin and Ferraz, performed in six consecutive steps: (1) initial translation; (2) compatibility of translations; (3) back-translation; (4) expert committee; (5) user evaluation; (6) final synthesis.⁽¹⁰⁾

In step 1, the instrument was translated from Spanish into Portuguese by two Brazilian translators fluent in Spanish. Each translator produced an independent version, called translation 1 (T1) and translation 2 (T2).

In step 2, the synthesis of translations was performed through consensus between the two translators and two nurse researchers who worked in the field of Oncology. Necessary changes were made, which gave rise to the synthesis version of the initial translations, called the consensus version between T1 and T2.

In step 3, the consensus version between T1 and T2 was back-translated from Portuguese to Spanish (natives in Spanish, fluent in Brazilian Portuguese). Each back-translator produced a new version, called back-translation 1 (B1) and back-translation 2 (B2). The aim of this step was to evaluate the similarities

between contents of consensus versions T1 and T2, and the original document.

In step 4, the Delphi technique was used to obtain a consensus of opinions from experts, considering that the properties of using the technique in the health sciences include the identification and formulation of standards or guidelines for theoretical and methodological issues, and the consensus on recommendations for action.^(11,12) A committee of experts composed of ten professionals in the field of Oncology, selected through their curriculum vitae of the Lattes Platform of CNPq (National Council for Scientific and Technological Development, Brazil – <https://buscatextual.cnpq.br/buscatextual/busca.do>) was formed. Ten professionals were selected, to whom the invitation letter was sent and of these, all returned with their consent, comprising four nurses, two physicians, two psychologists, a physical therapist and a nutritionist.

According to the literature on the Delphi technique, the number of experts recommended to compose the committee should vary from 10 to 18, not exceeding 30, thus, there is no need for statistical representation. The specificity and sensitivity should be the base of what is intended to be evaluated for the selection of participants, in this case, all professionals directly linked to the care of breast cancer survivors.⁽¹³⁾

The professionals were classified using criteria proposed by Fehring, which are based on the degree, specialization, scientific production, knowledge and time working on the topic under discussion, establishing a minimum score of 5 points.⁽¹⁴⁾

The evaluation form was sent to the experts, including a copy of the TSSCP-S translated from Spanish into Portuguese and a description of the evaluation process. The evaluators were asked to rate the model based on the 21-item evaluation form contained in the original study proposed by Ashing et al., on a 5-point Likert scale (1. Poor; 2. Fair; 3. Good; 4. Great; 5. Excellent) to assess the following domains: content, clarity, usefulness, cultural responsiveness, and socioecological responsiveness.⁽⁸⁾

At the end of each plan session, participants selected the following options: keep the item in its entirety, change it, or delete it. When choos-

ing the option to change, the participant was instructed to describe a writing suggestion and, when choosing the delete option, to justify the reason(s).

In step 5, the adoption of the study design was based on the participatory and collaborative approach between partners, researchers and the community, with the purpose of producing comprehensive care centered on the patient and on QoL, also in accordance with the original study.^(8,15) This step took place with participation of 18 breast cancer survivors, 12 from the A.C. Camargo Cancer Center, assisted by supplementary health, and six from Hospital São Paulo, the university hospital of the Universidade Federal de São Paulo, users of the Unified Health System (Brazilian SUS). The aim of this step was to produce a Brazilian Portuguese version of the Treatment Summary and Survivorship Care Plan (TSSCP-P) that would meet the needs of the target audience.

Participants (breast cancer survivors) were recruited between June and July 2020 through the schedule of follow-up consultations of Mastology Outpatient Clinics from both institutions, considering the following eligibility criteria: age over 18 years, literate, who completed treatment for breast cancer (except endocrine therapy) in the previous five years (2013 to 2018), with diagnoses at different stages and who agreed to participate in the study.

Patients participated in an individual interview lasting 20-60 minutes in the premises of the respective institutions, before and or after the follow-up appointment. At that moment, two instruments were delivered: sociodemographic and clinical characteristics, and the TSSCP-P, consisting of 33 sessions, followed by a 5-point Likert scale, ranging from 5 (I totally disagree) to 1 (I totally agree). For cases of disagreement or neutrality, a space was kept for comments and suggestions.

In Step 6, final synthesis, the statistical analyzes and the qualitative analysis of participants' contributions were gathered, producing the final version of the TSSCP-P.

The Statistical Package for the Social Sciences (SPSS), version 20.0 and Excel[®] were used in data-

base preparation and management, and in statistical analysis.

The index of agreement was calculated using the Content Validation Coefficient (CVC), proposed by Hernandez-Nieto.⁽¹⁶⁾ From the suggested formula, the CVC of each item and the total CVC of evaluations of experts and female breast cancer survivors were determined, considering the instrument sessions and the 21-item form to assess the categories, content, clarity, usefulness, cultural and socioecological responsiveness.⁽⁸⁾ Agreement $\geq 80\%$ and a CVC > 0.80 in the total result were considered adequate.

The process for adapting the TSSCP-S to Brazilian Portuguese was previously authorized by the research coordinator Dr. Kimlin Tam Ashing, City of Hope National Medical Center, California, United States. Subsequently, approvals were obtained from the Research Ethics Committees, complying with requirements of Resolution CNS 466/2012 that regulates research involving human beings at the Universidade Federal de São Paulo under protocol number. 3.272.493/2019 and of the Fundação Antônio Prudente under number 3.351.638/2029 (Certificate of Presentation of Ethical Appreciation: 04281018.5.1001.5505). All participants signed the Informed Consent form.

Results

In step 1 (initial translation), the most common disagreements in the translations were related to terms with the same meaning in Portuguese, such as *recorrência* and *recidiva* (recurrence and relapse); *grave* and *severo* (serious and severe); *doença* and *patologia* (disease and pathology); *dentário* and *bucal* (dental and oral). There was also disagreement about terms in the English language, such as status and condition. Regarding step 2 (compatibility of translations), involving the synthesis of translations, all disagreements identified were analyzed and defined by terms in Portuguese that are the most used in the health area, and it was necessary to keep similar terms in parentheses.

In step 3 (back-translation), back-translated versions B1 and B2 were identical in 27 (81.8%) sessions. In the remaining content, all differences in back-translations were considered synonymous terms and, thus, corresponding to the original instrument. In step 4 (committee of experts), there was participation of the committee of experts, who made relevant cross-cultural changes, improvements and adaptations in order to produce the version used in step 5 (user evaluation), in which the instrument was evaluated by women breast cancer survivors. As for the experts who composed the committee, the average score in the criteria proposed by Fehring⁽¹¹⁾ was 9.9 (ranging from 6 to 13). The categories analyzed by these participants generated agreement of 93.3% with a CVC of 0.93, as follows: 100.0% for content, 95.0% for clarity, 90.0% for usefulness, 90.0% for cultural responsiveness and 95.0% for socioecological responsiveness. When checking the items that made up the 34 sessions of the TSSCP-S in the first round, the result was a CVC of 0.61%, with an overall agreement of 60.9%, indicating the need for a second round.

In the second round, the complete instrument was sent together with the guidance of evaluating only the 15 sessions that were changed. In this round, a CVC of 0.83 was obtained, with an overall agreement of 83.3%, maintaining the participation of the ten specialists. The experts' evaluation resulted in the modification of 33 out of the 34 sessions of the TSSCP-S, and the definition of excluding a session that presented information about breast cancer in Latin women in the United States of America, resulting in the instrument version called pre-final. In step 5, women breast cancer survivors presented the following sociodemographic and clinical characterization (Table 1).

Table 1. Sociodemographic and clinical characteristics of the 18 participants of the Brazilian version of the Treatment Summary and Survivorship Care Plan (TSSCP-P)

Sociodemographic and clinical characteristics	n(%)
Age	
Mean (standard deviation)	53.6(10.6)
Minimum-Maximum	31-76

Continue...

Continuation.

Sociodemographic and clinical characteristics	n(%)
Age at diagnosis	
Mean (standard deviation)	53.6(10.6)
Minimum-Maximum	29-72
Type of access to treatment	
Insurance	11(61.1)
SUS	6(33.3)
Private	1(5.5)
Marital status	
Married/common law marriage	7(38.8)
Divorced	5(27.8)
Single	4(22.2)
Widow	2(11.1)
Education	
Tertiary	9(50.0)
Secondary	4(22.2)
Primary	5(27.8)
Occupational status	
Working at the moment	9(50.0)
Retired	7(38.8)
Unemployed	1(5.6)
Medical leave	1(5.6)
Belief	
Catholic	7(38.9)
Evangelical	4(22.2)
Spiritist	3(16.7)
Others	2(11.1)
None	2(11.1)
Socioeconomic class	
Class A	1(5.6)
Class B	10(55.5)
Class C	6(33.3)
Class D-E	1(5.6)
Comorbidity	
Endocrine diseases	6(30.0)
Dyslipidemia	5(25.0)
Systemic arterial hypertension	4(20.0)
Musculoskeletal disease	2(10.0)
Depression	2(10.0)
Asthma	1(5.0)
Endocrine therapy	
Yes	13(72.2)
No	5(27.8)
Molecular subtype	
Luminal B	8(44.4)
Luminal A	4(22.2)
Triple negative	3(16.7)
HER2 overexpression	3(16.7)
Pathological staging	
I	8(44.4)
II	5(27.8)
III	4(22.2)
IV	1(5.6)
Treatment	
Surgery + antineoplastic Ctx + RTx	12(66.7)
Surgery + antineoplastic Ctx	3(16.6)
Surgery + RTx	2(11.1)
Surgery	1(5.6)
Lymphedema	
No	17(94.4)
Yes	1(5.5)

CTX - Chemotherapy; RTx - Radiotherapy

In the assessment of agreement among women breast cancer survivors regarding the pre-final version, the result was a CVC of 0.94 with of 93.9%. Of the 33 sessions evaluated, 11 (33.3%) obtained the concept ‘I totally agree’ and the others ranged from 75 to 94.7%, with the concept ‘I partially agree’. The exclusion of any TSSC-P agreement session was not suggested. Table 2 shows the detailed data and agreement between expert evaluators in both rounds, and of women breast cancer survivors.

In step 6, final synthesis, the TSSCP-S, which in its original version contained 34 sessions, as detailed in column one of table 2, after the steps covered, is now called TSSCP-P: *Resumo do Tratamento e Plano de Cuidados*

para a Sobrevivente de Câncer de Mama, containing 33 sessions, excluding session three that contained information about breast cancer in Latin women residing in the United States of America. The Brazilian version of the TSSCP-S is available in annex 1.

Discussion

The present study was based on a methodological framework anchored in international studies and guidelines, with the care of women who survived breast cancer as its central object, using an innovative tool that promotes QoL.^(8,10)

Table 2. Agreement in relation to evaluation of specialists and female breast cancer survivors regarding the Treatment Summary and Survivorship Care Plan (TSSCP-S)

Item evaluated per session	Committee of experts				Women breast cancer survivors	
	1 ^a Round		2 ^a Round		CVC	Concordance (%)
	CVC	Concordance (%)	CVC	Concordance (%)		
S1. Title	0.50	50.0	NA	NA	1.00	100.0
S2. Importance of the care plan for survival	0.70	70.0	NA	NA	1.00	100.0
S3. Information on breast cancer in Latin women in the United States of America	0.30	30.0	0.90	90.0	0.94	94.4
S4. Importance of the TSSCP-S	0.70	70.0	NA	NA	0.83	83.3
S5. What is a survival care plan?	0.50	50.0	NA	NA	0.83	83.5
S6. Why do I need a survival care plan	0.40	40.0	NA	NA	1.00	100.0
S7. Information on breast cancer	0.70	70.0	NA	NA	0.94	94.4
S8. How to use TSSCP-S	0.80	80.0	NA	NA	0.89	88.9
S9. General information (personal and cancer diagnosis data)	0.60	60.0	NA	NA	1.00	100.0
S10. General information (tumor characteristics, reconstruction and genetic testing)	0.40	40.0	1.00	100.0	0.94	94.4
S11. Information about chemotherapy	0.40	40.0	1.00	100.0	0.67	72.2
S12. Information about radiotherapy	0.40	40.0	1.00	100.0	0.89	86.9
S13. Follow-up care and surveillance	0.70	70.0	0.80	80.0	0.94	94.4
Session 14: Care team	0.60	60.0	0.60	60.0	0.89	88.9
S14. Family history and clinical conditions	0.70	70.0	0.60	60.0	0.94	94.4
S16. Contextualization on health advice	0.80	80.0	NA	NA	1.00	100.0
S17. Advice on risk of relapse	0.50	50.0	NA	NA	1.00	100.0
S18. Advice on relapse symptoms	0.70	70.0	NA	NA	1.00	100.0
S19. Advice on lymphedema	0.60	60.0	NA	NA	0.94	94.4
S20. Recommendations for preventive care	0.70	70.0	NA	NA	0.89	88.9
S21. Vaccination advice	0.80	80.0	0.70	70.0	0.89	88.9
S22. Medication advice	0.70	70.0	NA	NA	0.94	94.4
S23. Nutrition advice	0.60	60.0	NA	NA	0.94	94.4
S24. Advice on maintaining a healthy weight	0.70	70.0	0.80	80.0	0.94	94.4
S25. Advice on managing stress and wellbeing	0.70	70.0	0.80	80.0	1.00	100.0
S26. Advice on hydration	0.60	60.0	NA	NA	1.00	100.0
S27. Advice on alcohol, cigarettes and prescription drugs	0.60	60.0	0.90	90.0	1.00	100.0
S28. Advice on reproductive health	0.60	60.0	NA	NA	0.94	94.4
S29. Advice on communicating with the healthcare professional	0.50	50.0	0.90	90.0	0.94	94.4
S30. Advice on bone health	0.70	70.0	0.90	90.0	0.94	94.4
S31. Advice on oral health	0.80	80.0	NA	NA	0.94	94.4
S 32. Advice on heart health	0.60	60.0	NA	NA	1.00	100.0
S33. Advice on other medical exams	0.60	60.0	0.90	90.0	0.89	88.9
S34. Questions about QoL	0.50	50.0	0.90	90.0	1.00	100.0
Mean	0.61	60.9	0.83	83.3	0.94	93.9

NA - Not evaluated; S - Session; CVC - Content Validity Coefficient

The process of translating an instrument with the intention of adapting it to the reality of the target population is complex, comprises reliable valid grammatical and cultural adjustments directed to the population for which it is intended. The methodological approach must preserve the equivalence between the original source and the target language, guarantee the target audience's understanding of contents and, in the case of educational material, increase adherence to treatment, self-monitoring and self-management, in addition to favoring effective professional-user communication.^(17,18)

The content validation of the present investigation involved the participation of members of the multidisciplinary team involved in the care of cancer survivors. When validating the content of an instrument, it is essential that participants know the needs and specificities of the target population, so that the final version is scientifically correct and relevant, as well as effective.^(18,19) In this sense, the group of expert participants fulfilled the requirements.

The first round of Delphi promoted intense debate and many concerns, observed in the percentages of agreement of items between 50 and 80%. The consensus of experts named the new version for TSSCP-P: *Resumo do Tratamento e Plano de Cuidados para a Sobrevivente de Câncer de Mama*, even though the possibility of keeping it in the language of origin was given, showing concern with comprehensibility to the final user.

In the present investigation, the cultural and socioecological domains were highlighted as a welcome addition to the need for multidimensional exploration of contents to be validated. The improvement of understanding of the phenomenon studied, focusing on social and cultural contexts, has shown to enhance actions that improve the health and wellbeing of the target population.⁽²⁰⁾ Information similar to cultural values and socioecological issues impact on outcomes of cancer survival and follow-up care.^(8,15)

The sociodemographic and clinical profile of survivors participating in the evaluation phase was heterogeneous, including women in different age groups, socioeconomic levels, educational level, histological types of breast cancers, molecular pro-

files, stages and types of treatments. This diversity of characteristics contributed to semantic equivalence, generated changes in technical terms of the health area and influenced the judgment of the material evaluated, allowing a more realistic scenario with several factors interrelated with the needs and spectrum of resources.^(8,21)

The survival care plan must be able to inform about the journey taken in the process of becoming ill with cancer, and educate survivors and health care providers about the transition from cancer treatment to follow-up care, with consequent improvement in the amount of information provided, as well as in the quality of communication and coordination between health professionals and patients.^(22,23)

In this sense, validating the educational material with the target audience was essential and the literature reinforces the benefits also perceived in this study. Content validation with the target audience favors the perception of what is missing, what is not understandable, the distance between what is written and what is understood, mainly by aligning what is intended to be informed with what the target population considers as really important, making it understandable to as many people as possible.⁽²⁴⁾

One session was excluded from the plan and all others were changed. An important aspect in the validity of educational materials concerns sufficiency, addressing relevant and essential items and avoiding items that generate doubts or duplicity of meanings.⁽¹⁸⁾ In the process of cross-cultural adaptation, the original and final versions are equally important, and both are subject to change. Therefore, items considered irrelevant, inappropriate or ambiguous can be changed or excluded, or necessary and appropriate items to the culture can be added.⁽¹⁰⁾

A limitation of the present study was the cultural regionality of breast cancer survivors participating in the validation. Even though they represent different socioeconomic and educational conditions, these were exclusive residents of the southeastern region of the country. The other limitation is the temporal effect of guidelines contained in the plan,

as these may be modified according to established public policies and/or new scientific evidence.

In the follow-up phase of women diagnosed and treated for breast cancer, the TSSCP-P can be used as a strategic form of therapeutic support and a safe source of information for these women survivors in order to bring knowledge about the therapeutic itinerary followed and favor the adoption of behaviors and attitudes that provide health, quality of life and wellbeing, since it contains a lot of information that strives to educate the surviving woman for self-management of care.

Conclusion

The TSSCP-S was translated, cross-culturally adapted to Brazilian Portuguese, resulting in the TSSCP-P: *Resumo do Tratamento e Plano de Cuidados para a Sobrevivente de Câncer de Mama*, with valid reliable content directed to the target population. Considering the methodological rigor and the achievement of good agreement rates, this plan is validated and viable for use in the follow-up of women who have survived breast cancer.

Acknowledgements

To the National Council for Scientific and Technological Development (CNPq), level 2 research productivity grant, process PQ 306687/2018-6 to Edvane Birelo Lopes De Domenico. To the Coordination for the Improvement of Higher Education Personnel (CAPES), Capes-PRINT Program, process number 88881.311044/2018-00, Oncology.

Collaborations

Matsubara MGS, Guimarães RE, Makdissi FB, Elias S, Bergerot CD, Ashing KT and De Domenico EBL collaborated with the study, analysis and interpretation of data, writing of the article, relevant critical review of the intellectual content and approval of the final version to be published.

References

- Allemani C, Matsuda T, Di Carlo V, Harewood R, Matz M, Nikšić M, Bonaventure A, Valkov M, Johnson CJ, Estève J, Ogunbiyi OJ, Azevedo E Silva G, Chen WQ, Eser S, Engholm G, Stiller CA, Monnereau A, Woods RR, Visser O, Lim GH, Aitken J, Weir HK, Coleman MP; CONCORD Working Group. Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *Lancet*. 2018;391(10125):1023-75.
- Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA). Estimativa 2020: incidência de câncer no Brasil. Rio de Janeiro: INCA; 2020 [citado 2020 Jun 10] Disponível em: <https://www.inca.gov.br/publicacoes/livros/estimativa-2020-incidencia-de-cancer-no-brasil>
- National Cancer Institute (NIH). Surveillance, epidemiology, and end results program 2011-2017. USA: NIH; [cited 2021 Aug 17]. Available from: <https://seer.cancer.gov/statfacts/html/breast.html>
- Oliveira RA, Zago MM, Thorne SE. Interaction between professionals and cancer survivors in the context of Brazilian and Canadian care. *Rev Lat Am Enfermagem*. 2017;25(0):e2972.
- American Society of Clinical Oncology (ASCO). Cancer.Net. ASCO Cancer Treatment and Survivorship Care Plans. USA; ASCO; 2020 [cited 2020 Apr 12]. Available from: <https://bit.ly/2Gkv9Xq>
- Gjerset GM, Loge JH, Kiserud CE, Fosså SD, Gudbergsson SB, Oldervoll LM, et al. Perceived needs for different components in a rehabilitation program among cancer survivors with chronic fatigue compared to survivors without chronic fatigue. *Acta Oncol*. 2017;56(2):245-53.
- Ellegaard MB, Grau C, Zachariae R, Bonde Jensen A. Fear of cancer recurrence and unmet needs among breast cancer survivors in the first five years. A cross-sectional study. *Acta Oncol*. 2017;56(2):314-20.
- Ashing K, Serrano M, Weitzel J, Lai L, Paz B, Vargas R. Towards developing a bilingual treatment summary and survivorship care plan responsive to Spanish language preferred breast cancer survivors. *J Cancer Surviv*. 2014;8(4):580-94.
- Joshi A, Larkins S, Evans R, Moodley N, Brown A, Sabesan S. Use and impact of breast cancer survivorship care plans: a systematic review. *Breast Cancer*. 2021;28(6):1292-317.
- Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*. 2000;25(24):3186-91.
- Niederberger M, Spranger J. Delphi Technique in health sciences: a map. *Front Public Health*. 2020;8:457.
- Zarili TF, Nemes MI. Técnica Delphi no processo de validação do Questionário de Avaliação da Atenção Básica (QualiAB) para aplicação nacional. *Saude Soc*. 2021;30(2):e190505.
- Foster J, Stanek K. Cross-cultural considerations in the conduct of community-based participatory research. *Fam Community Health*. 2007;30(1):42-9.
- Fehring RJ. Methods to validate nursing diagnoses. *Heart Lung*. 1987;16(6 Pt 1 6-I):625-9.
- Ashing-Giwa KT. The contextual model of HRQoL: a paradigm for expanding the HRQoL framework. *Qual Life Res*. 2005;14(2):297-307.
- Hernández-Nieto RA. Contributions to statistical analysis. Mérida: Universidad de Los Andes; 2002. 228 p.

17. Jacobsen PB, DeRosa AP, Henderson TO, Mayer DK, Moskowitz CS, Paskett ED, et al. Systematic Review of the Impact of Cancer Survivorship Care Plans on Health Outcomes and Health Care Delivery. *J Clin Oncol*. 2018;36(20):2088–100.
18. Leite SS, Afio AC, Carvalho L, Silva JM, Almeida PC, Pagliuca LM. Construção e validação de Instrumento de Validação de Conteúdo Educativo em Saúde. *Rev Bras Enferm*. 2018;71(4):173–8.
19. Lins ML, Evangelista CB, Gomes GL, Macedo JQ. Autocuidado domiciliar após cirurgias ginecológicas: elaboração e validação de material educativo. *Acta Paul Enferm*. 2021;34:eAPE03154.
20. Lyson HC, Haggstrom D, Bentz M, Obeng-Gyasi S, Dixit N, Sarkar U. Communicating critical information to cancer survivors: an assessment of survivorship care plans in use in diverse healthcare settings. *J Cancer Educ*. 2021;36(5):981–9.
21. Ashing KT, Lai L, Brown S, McDowell K, Carter D, Smith J, et al. Developing a treatment summary and survivorship care plan responsive to African-American breast cancer survivors. *Psychooncology*. 2016;25(6):729–31.
22. Hua A, Sesto ME, Zhang X, Wassenaar TR, Tevaarwerk AJ. Impact of survivorship care plans and planning on breast, colon, and prostate cancer survivors in a community oncology practice. *J Cancer Educ*. 2020;35(2):249–55.
23. International Test Commission (ITC). The ITC Guidelines for Translating and Adapting Tests. England; ITC; 2017 [cited 2021 Oct 17]. Available from: www.InTestCom.org
24. Ximenes MA, Fontenele NA, Bastos IB, Macêdo TS, Galindo Neto NM, Caetano JA, et al. Construction and validation of educational booklet content for fall prevention in hospitals. *Acta Paul Enferm*. 2019;32(4):433–41.