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ORIGINAL ARTICLE

VALIDATION OF THE CANCER SURVIVORS' UNMET NEEDS QUESTIONNAIRE - CaSUN FOR BRAZILIAN CULTURE

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ABSTRACT

Objective: to carry out the cross-cultural adaptation and validation of the *Cancer Survivors' Unmet Needs* questionnaire for Brazilian culture, with a focus on women with breast cancer. **Method:** methodological study carried out between May 2024 and February 2025, in two stages: 1) translation and cross-cultural adaptation, and 2) validation of psychometric properties. Seven people participated in the first stage, and 214 cancer survivors participated in the second. Participants in the second stage completed the sociodemographic and clinical questionnaires, as well as the translated and adapted Cancer Survivors' Unmet Needs questionnaire. For data analysis, *Cronbach*'s alpha and Kappa coefficients were calculated, and a factor model of multivariate analysis was fitted. **Results:** The factor analysis revealed that some factors migrated, but without the need to alter the original structure. *Cronbach*'s alpha was 0.88, indicating acceptable internal consistency, and the reliability using the Kappa test was 0.86, indicating almost perfect agreement. **Conclusion:** The Brazilian version of the *Cancer Survivors' Unmet Needs* questionnaire adhered to the original structure, demonstrating adequate internal consistency and reliability, and revealed that the questionnaire is valid for measuring the unmet needs of breast cancer survivors.

Keywords: Survivors. Breast Neoplasms. Adult Health. Health Service Needs and Demands. Validation Study.

INTRODUCTION

The number of people living after a cancer diagnosis has increased significantly in recent decades, reflecting advances in early detection strategies and antineoplastic treatments[1,2]. This progress has led to an increase in survival rates and contributed to the consolidation of the concept of "cancer survivor". According to the American Cancer Society[3], a cancer survivor is any individual from the moment they are diagnosed with the disease, regardless of the clinical course or outcome.

The concept described above considers that there is no single type of survivor, as there are those who live with cancer and those who are free of the disease. The expression should be used for individuals with a history of cancer from diagnosis and throughout their lives[4]. The term is intended to describe the process of living with, through, and beyond cancer[5].

With the increase in survival rates, it has been possible to monitor the repercussions and needs faced by cancer survivors. Physical, psychosocial, and financial changes resulting from the disease and its treatment, both in the short and long term, are present in their daily lives. Consequently, impaired quality of life and unmet supportive care needs are part of their life itinerary[6].

The study carried out in North America with 335 cancer survivors showed that only 29.9% of survivors had all their needs met. The greatest needs focused on stress reduction, worries about cancer recurrence, and problems with life[7].

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Another study carried out in Canada with 10,717 adult cancer survivors revealed that 84% of the sample had at least one unmet need, the most frequent being emotional, physical, and practical concerns. Along these lines, the review that identified the care needs of breast cancer survivors highlighted that the most relevant were psychological, followed by those related to the health system and interpersonal[8].

Female breast cancer is the most common cancer worldwide, accounting for 2.3 million new cases[9]. According to the study[10] which analyzed survival in women diagnosed with non-metastatic breast cancer between 2010 and 2021, 89.9% of the participants had a 60-month survival rate, constituting a group of patients who do not have the disease but will need future care. In Brazil, the estimate for this type of cancer for the three years 2023-2025 is 74,000 cases[9], and there is no mention of cancer survivors in the National Policy for Cancer Prevention and Control[11]. As a result, there are few policies aimed at this growing portion of the population, which represents a significant challenge for public and private health services, since the resources to support survivors are different from those required for treatment.

The review[12] that synthesized the evidence on the management of the sequelae of a breast cancer diagnosis pointed out that women who survive this type of cancer can experience significant after-effects of treatment. These can persist throughout their lives and may limit their quality of life. Thus, identifying the unmet needs of these individuals can help managers, health professionals, and the survivors themselves to develop personalized interventions.

To assess the unmet needs of cancer *survivors*, the *Cancer Survivors' Unmet Needs* (CaSUN) questionnaire was developed in 2007. However, its application in the Brazilian context requires cross-cultural adaptation and validation. Thus, this study aims to carry out the cross-cultural adaptation and validation of the *Cancer Survivors' Unmet Needs* questionnaire for Brazilian culture, with a focus on women with breast cancer.

METHOD

The methodological study, carried out between May 2024 and February 2025, used the World Health Organization's (WHO) method of translation and cross-cultural adaptation of measuring instruments[13] which is composed of two stages: 1) translation and cross-cultural adaptation, and 2) validation of psychometric properties.

We chose to adopt the WHO method because it has been used in other CaSUN translation studies[14,15]. The phases of stage 1 were 1) translation by two independent bilingual translators; 2) a consensus meeting between the two translators; 3) review of the translations by a group of four monolingual individuals; 4) meeting between the translators to review the notes made by the monolingual group; 5) sending the translated document to a third translator for back-translation, in other words, translation into the original language; and 6) the group of bilingual experts reviewed translations and back-translations to determine the accuracy and equivalence of the translation process. Finally, the questionnaire was sent to the authors for approval.

A total of seven individuals participated in this stage of the research: two bilingual translators, four monolingual participants, and one professional translator. In stage 2, the CaSUN, translated and adapted to Brazilian culture, was applied to a sample of 214 breast cancer survivors from a referral hospital for cancer treatment located in a capital city in southern Brazil. The sample was defined based on the precepts of Pasquali[16], who recommends recruiting five to ten participants for each item in the instrument. The inclusion criteria at this stage were being aged 18 or over, having completed primary treatment for breast cancer at least a year ago, and having a follow-up appointment at the study hospital.

Each participant answered the sociodemographic, clinical, and CaSUN translated and adapted questionnaires, both printed, according to stage 1. The sociodemographic questionnaire contained questions about gender, education, income, marital status, and profession. The CaSUN is a free questionnaire comprising 42 items, 35 of which pertain to unmet needs, six to positive changes, and one open-ended question. It has five domains: 1) existential survival (14 items), 2) comprehensive cancer treatment (6 items), 3) information (3 items), 4) quality of life (2 items), and 5) relationships (3 items)[17]. It has already been adapted and used in several countries, such as China, Spain, the Netherlands, and Japan.

When filling in the CaSUN, participants indicated whether the need had been met or not. The self-perceived strength of the unmet need was marked as weak, moderate, or vigorous. The total CaSUN score ranges from 0 to 35 points, corresponding to the sum of all required items, with higher scores indicating greater unmet needs. The last seven items of the questionnaire are excluded from the calculation of the total score.

The data collected was entered into Excel by two members of the research team and summarized by calculating simple frequencies and percentages. STATISTICA version 7 statistical software was used to assess the internal consistency of the questionnaire, and Cronbach's alpha coefficient was obtained. The reliability of the questionnaire was verified by calculating the Kappa coefficient. To confirm the definition of the domains of the CaSUN questionnaire, the collected data were analyzed using multivariate factor analysis, considering five factors extracted using the principal components method and Varimax rotation. The same items from the original CaSUN manual[18] were considered in this analysis.

Regarding the ethical aspects, the project was approved by the Research Ethics Committee with opinion number. 6,872,231, and all participants signed the Informed Consent Form.

RESULTS

Stage 1

In phases one and two, the seven participants consisted of three translators (two female and one male) and four community members: a secretary, a student, an administrative technician, and a housewife. During the translation phase, a discrepancy arose regarding the answer option "Need is currently unmet—how strong is your need?" At the consensus meeting, the translators opted to keep the translation "Need not met so far—how strong is your need?".

In the third phase, after the translators' consensus was reached, participants received the questionnaire. They had doubts about the verb tenses of all the items. They chose to change the items beginning with a verb to the past tense, since they were experiences that had already been lived or were in progress. The answer option that the translators disagreed with in the initial translation was also discussed at this stage and changed to "need has not been met—how strong is your need?". Items 3, 4, 5, 7, 13, and 16 underwent minor adjustments (substitution of some words) for better understanding.

The monolingual members' version was reviewed by the initial translators, who accepted all the proposed changes, assuming they did not alter the meaning of any item in the questionnaire. In the back-translation, a third translator received the questionnaire, and the only discrepancy in the inverted translation was in the answer option "need not met", with the back-translator proposing "How much did you need?" with the options changing from "somewhat, moderately, very unmet".

At the review meeting held by the initial translators, the back-translator's proposal was accepted, and the words "need not met - How strong was your need?" were changed to "need not met - How much did you need?" and the options "little, medium, a lot" were changed. The translation and cross-cultural adaptation stage was completed when the questionnaire was sent to the authors.

Stage 2

A total of 214 cancer survivors took part in this stage, with an average age of 57 years (29-88); 113 were married or in a stable union, 41 were single, 63 were retired, 60 had a steady job, and 54 worked from home; the family income of 141 participants ranged from one to three minimum wages (Table 1).

Table 1. Sociodemographic characteristics of participants in stage 2 of the study. Curitiba - PR, Brazil, 2025

Cancer survivors		
Age	**f**	**%**
18 to 30 years	1	0.46
31 to 59 years	116	54.2
Over 60	97	45.32
Education		

Illiterate	2	0.9
Incomplete fundamental education	29	13.6
Completed elementary school	41	19.2
High school incomplete	11	5.1
Completed high school	73	34.1
Incomplete higher education	14	6.5
Completed higher education	44	20.6
Marital status		
Married / stable union	113	52.8
Single	41	19.2
Divorced	36	16.8
Widow/other	24	11.2
Occupation		
Employee	60	28
Autonomous	23	10.7
Unemployed	15	7
The household	40	18.7
Retired	64	29.9
Another	12	5.6
Family income		
No income	4	1.9
Up to 1 SM*	12	5.6
1 to 3 SM	141	65.9
4 to 10 SM	56	26.2
Up 10 SM	1	0.5

* SM = Brazilian minimum wage - approximately 261 US dollars.
f- frequency; % - percentage

The total internal consistency was 0.88, a result considered acceptable. *Cronbach*'s alpha yielded better results in the "survival" and "quality of life" domains. The "comprehensive cancer care," "relationships," and "information" domains obtained a Cronbach's alpha of less than 0.70, indicating that there may be items in these domains that require revision (Table 2).

Table 2. Internal consistency of the CaSUN domains. Curitiba - PR, Brazil, 2025

Domain	Cronbach's alpha
Existential survival	0.88
Comprehensive cancer care	0.59
Information	0.69
Quality of life	0.72
Relationships	0.68
TOTAL	**0.88**

Factor analysis revealed that the factors in the Brazilian version of CaSUN did not align with the factors in the original version. The items whose factors were different were 1, 2, 3, 18, 22, 23, 24, 25, 26, 27, 29, 31, 34, as shown in Chart 1.

Chart 1. Factor analysis of CaSUN items. Curitiba, PR, Brazil, 2025

Item	Factor corresponding to the Brazilian CaSUN item (loadings)					Factor from the original questionnaire
	F1	F2	F3	F4	F5	CASUN
1	-0.058	0.622	0.045	0.125	0.228	F3
2	0.003	0.157	0.021	0.701	-0.057	F3
3	-0.038	0.756	0.051	0.400	0.004	F3
4	0.066	0.713	-0.117	0.350	-0.050	F2
5	-0.002	0.727	-0.058	0.267	-0.031	F2

6	0.053	0.649	0.049	-0.209	-0.050	F2
7	0.015	0.776	-0.023	-0.136	-0.004	F2
8	0.138	0.689	0.110	0.041	-0.151	F2
10	0.719	0.141	-0.059	0.417	0.020	F1
11	0.252	0.184	-0.035	0.661	0.276	F4
12	0.346	0.087	0.296	0.537	-0.047	F4
18	0.058	-0.047	0.174	0.063	0.725	F2
19	0.776	0.040	0.268	0.360	-0.095	F1
20	0.685	-0.032	0.217	0.458	-0.057	F1
21	-0.040	-0.062	0.539	0.039	0.546	F5
22	-0.029	0.023	0.698	0.022	0.371	F5
23	0.360	-0.114	0.486	0.130	-0.011	F1
24	0.070	-0.043	0.605	0.425	0.078	F1
25	0.123	0.027	0.702	0.229	0.112	F1
26	0.284	-0.006	0.625	0.051	-0.149	F1
27	0.153	0.094	0.736	-0.063	0.124	F5
29	0.213	0.011	0.073	0.034	0.875	F1
30	0.854	0.069	0.168	0.035	0.072	F1
31	0.397	0.149	0.516	-0.190	0.290	F1
32	0.624	0.107	0.262	-0.302	0.091	F1
33	0.768	-0.043	0.159	0.129	0.486	F1
34	0.185	0.084	0.324	0.633	0.147	F1
35	0.656	-0.078	0.081	0.070	0.476	F1

When verifying the questionnaire's reliability using the Kappa coefficient, the values were consistently above 0.86, indicating almost perfect agreement (Table 3).

Table 3. Reliability of the domains of the CaSUN Brazilian version. Curitiba - PR. Brazil, 2025.

DOMAIN	Kappa	CI (95%)
Existential survival	0.89	0.86 – 0.93
Comprehensive cancer care	0.89	0.85 – 0.93
Information	0.89	0.85 – 0.94
Quality of life	0.94	0.90 – 0.99
Relationships	0.92	0.88 – 0.96
TOTAL	**0.86**	**0.83 – 0.89**

CI = confidence interval.

The translated version of CaSUN into Brazilian Portuguese is available in the QR code below:

Figure . CaSUN adapted and validated for Brazilian culture. Curitiba, PR, Brazil, 2025.

DISCUSSION

Regarding the sociodemographic characteristics of the participants in stage 2, the age results are in line with the study that developed the CaSUN[17] as well as the Spanish[19] and Chinese[20] validations, and with the national literature, which indicates that the occurrence of cancer is higher in the 50-

year age group[9]. However, this differs from the results of the Korean study[21], which identified the prevalence and predictors of unmet needs of lung cancer patients undergoing surgical resection in Seoul, whose average age was 63 years.

Concerning income, there was a predominance of participants with incomes between one and three Brazilian minimum wages (R$1,518.00 to R$4,554.00), a figure considerably lower than that reported in the study that shortened CaSUN in Taiwan[22], whose income range varied from less than US$1,000 to more than US$3,333, approximately between R$5.500,00 and R$18.000,00. Despite this economic discrepancy between the samples, it is essential to note that the participants in this study were treated by the Unified Health System, which can directly influence the needs perceived as being met or not met, reflecting structural and access differences between the contexts analyzed.

When the psychometric properties of CaSUN were analyzed, the factor loadings found in this study indicated that the original five-factor structure was well-fitted. However, some items exhibited higher factor loadings in different factors of the original questionnaire. These differences point to possible cultural and contextual influences on the perception of needs among breast cancer survivors. However, it still confirms that CaSUN measures the five domains of the original questionnaire, and there is no need to add other domains to the questionnaire.

The factor loading result is similar to that of the Chinese study[23] conducted with patients diagnosed with various types of cancer (breast cancer 30.3%, gynecological 24.3%, head and neck 21.3%, gastric or colorectal cancer 10.7%), but differs from the study conducted in Taiwan[22] with breast cancer survivors, in which four domains were confirmed, namely "information", "physical and psychological effects," "communication," and "medical care". It also differs from the Korean study, which validated the CaSUN with lung cancer patients and identified three domains, and subsequently added a financial domain. The results of the Korean and Taiwanese studies suggest that specific types of cancer may have distinct needs.

The study conducted in Tauwan[22] reinforces that CaSUN is not a specific questionnaire and therefore needs to be adapted to address specific concerns. According to a Taiwanese study, mothers have needs related to their role that need to be addressed.

The study[24, which reflected on the experiences of women with breast cancer, observed a worsening of psychological suffering in relation to the disease among those who were mothers. Similarly, the study[25] that described the experiences of women regarding motherhood in the context of hospitalization for cancer found that being a mother emerged as a central aspect in the lives of the participants, with children being considered the greatest motivation for coping with the disease. Both studies highlight that, in various contexts, needs can vary depending on the type of cancer and emotional ties.

In addition to motherhood, the fact that the sample in this study was female may reveal what some authors[26] consider to be "women's characteristics", such as being a warrior, the foundation of the home, harmonizing the family, and enduring suffering, conditions that give a sense of naturalization of difficulties.

Regarding the reliability of the CaSUN, it was observed that Cronbach's alpha indicated high internal consistency, a result similar to that of the Chinese validation22, and at odds with the results of studies carried out in Japan[27] and Spain[28], which reported a Cronbach's alpha of 0.96.

When analyzing the Cronbach's alpha of each domain of the CaSUN, it was possible to observe that, although the total reliability is acceptable, the domains "comprehensive cancer care," "relationships," and "information" obtained unsatisfactory internal consistency, indicating that the set of items that make up these domains is inadequate to measure the desired construct. This result differs from the Japanese validation[27], which found Cronbach's alphas of 0.91, 0.82, 0.81, 0.78, and 0.71 in the domains of existential survival, comprehensive cancer care, information, quality of life, and relationships, respectively.

The Kappa test indicated almost perfect agreement between all items, allowing us to infer that CaSUN is a reliable questionnaire for measuring the unmet needs of breast cancer survivors among Brazilian women.

The limitations of this study lie in the fact that the sample in stage 2 was exclusively of women with breast cancer, meaning that it cannot be generalized to all cancer survivors. In addition,

data collection was conducted in a public service, where survivors were treated by both public and private health insurance, which did not allow for an assessment of needs across different social contexts.

CONCLUSION

The Brazilian version of the *Cancer Survivors' Unmet Needs* (CaSUN) followed the original structure, comprising five domains. It demonstrated adequate internal consistency and reliability, indicating that the questionnaire is a valid measure of the unmet needs of breast cancer survivors.

It is believed that the use of the Brazilian version of CaSUN will help identify the unmet needs of cancer survivors and provide healthcare teams and managers with an opportunity to expand care.

Future studies are recommended to test the questionnaire on other populations of cancer survivors, including men, individuals with different types of cancer, and patients cared for in other care settings, broadening the applicability and generalization of the results.

VALIDAÇÃO DO QUESTIONÁRIO CANCER SURVIVORS' UNMET NEEDS – CaSUN PARA A CULTURA BRASILEIRA

RESUMO

Objetivo: realizar a adaptação transcultural e validar o questionário *Cancer Survivors' Unmet Needs* para a cultura brasileira, com foco em mulheres com câncer de mama. **Método:** estudo metodológico realizado entre maio de 2024 e fevereiro de 2025, em duas etapas: 1) tradução e adaptação transcultural; 2) validação das propriedades psicométricas. Participaram da primeira etapa sete pessoas e da segunda, 214 sobreviventes do câncer. Os participantes da segunda etapa preencheram os questionários sociodemográfico e clínico e o *Cancer Survivors' Unmet Needs* traduzido e adaptado. Para a análise dos dados, foram obtidos os coeficientes alfa de *Cronbach* e Kappa, e ajustado modelo fatorial de análise multivariada. **Resultados:** a análise fatorial revelou que alguns fatores migraram, no entanto, sem necessidade de alteração na estrutura original. O alfa de *Cronbach* foi de 0,88, mostrando consistência interna aceitável, e a confiabilidade pelo teste de Kappa foi de 0,86, indicando concordância quase perfeita. **Conclusão:** a versão brasileira do *Cancer Survivors'Unmet Needs* acompanhou a estrutura original com cinco domínios, teve uma adequada consistência interna e confiabilidade, revelando que o questionário é válido para mensurar as necessidades não atendidas de sobreviventes do câncer de mama.

Palavras-chave: Sobreviventes. Neoplasias da Mama. Saúde do Adulto. Necessidades e Demandas de Serviços de Saúde. Estudo de Validação.

VALIDACIÓN DEL CUESTIONARIO CANCER SURVIVORS' UNMET NEEDS - CaSUN PARA LA CULTURA BRASILEÑA

RESUMEN

Objetivo: realizar la adaptación transcultural y validar el cuestionario *Cancer Survivors' Unmet Needs* para la cultura brasileña, con enfoque en mujeres con cáncer de mama. **Método**: estudio metodológico realizado entre mayo de 2024 y febrero de 2025, en dos etapas: 1) traducción y adaptación transcultural; 2) validación de las propiedades psicométricas. Participaron en la primera etapa siete personas y en la segunda, 214 sobrevivientes de cáncer. Los participantes de la segunda etapa rellenaron los cuestionarios sociodemográfico y clínico y el *Cancer Survivors' Unmet Needs* traducido y adaptado. Para el análisis de los datos, se obtuvieron los coeficientes alfa de *Cronbach* y Kappa, y ajustado modelo factorial de análisis multivariante. **Resultados**: el análisis factorial reveló que algunos factores migraron; sin embargo, no fue necesaria ninguna alteración en la estructura original. El alfa de *Cronbach* fue de 0,88, señalando consistencia interna aceptable, y la confiabilidad por la prueba de Kappa fue de 0,86, indicando concordancia casi perfecta. **Conclusión**: la versión brasileña del *Cancer Survivors'Unmet Needs* acompañó la estructura original con cinco dominios, tuvo una adecuada consistencia interna y confiabilidad, revelando que el cuestionario es válido para medir las necesidades no atendidas de sobrevivientes de cáncer de mama.

Palabras clave: Sobrevivientes. Neoplasias de la Mama. Salud del Adulto. Necesidades y Demandas de Servicios de Salud. Estudio de Validación.

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