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Cultural Adaptation Process of the Supportive Care Needs Survey for Mexican Patients with Breast Cancer

Proceso de adaptación cultural de la encuesta de necesidades de apoyo en la atención para pacientes con Cáncer de mama: estudio piloto

Carmen Lizette Gálvez-Hernández[1,2]
Instituto Nacional de Cancerología

Luis F. Oñate-Ocaña[3]
Instituto Nacional de Cancerología

Alejandro Mohar-Betancourt[2,3]
Instituto Nacional de Cancerología

Allison Boyes[4]
University of Newcastle

Verónica Neri-Flores[5]
Universidad Nacional Autónoma de México

Cynthia Villarreal-Garza[2,3,6]
Tecnológico de Monterrey

Breast cancer (BC) is a significant public health issue in Mexico. The understanding of how to meet patient's individual needs is essential to guide supportive care and improve quality of life among these patients. One of the most comprehensive tools for needs assessment is the Supportive Care Needs Survey Short Form-34 (SCNS-SF34), its validity and reliability has been robustly established in several languages, but there are no studies focusing on specific cultural features concerning Mexican women diagnosed with BC. Our objective was to describe and analyze the process of cultural adaptation of the SCNS-SF34 in Mexican women with BC through a pilot study. This process was performed following standardized procedures: a forward and backward translation by experts was undertaken in both languages and the translated version was piloted in 21 women with BC diagnosis. The results showed that appropriate adaptation of the SCNS-SF34 required both literal and sociocultural modifications, and highlighted that appropriate adaptation requires rigorous development methodology that takes into account cultural conditions as well as conceptual, linguistic and metric properties.

Keywords: Psychometrics; Psychological test; Needs assessment; Breast cancer; SCNS-SF34.

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1 Catedrática-CONACyT, Instituto Nacional de Cancerología
2 Joven y Fuerte: Programa para la Atención e Investigación de Mujeres Jóvenes con Cáncer de Mama, Mexico City
3 Departamento de Investigación, Instituto Nacional de Cancerología
4 School of Medicine & Public Health. Faculty of Health & Medicine. The University of Newcastle. Australia
5 Facultad de Psicología, Universidad Nacional Autónoma de México
6 Centro de Cáncer de Mama del Hospital Zambrano Hellion, Tecnológico de Monterrey, San Pedro Garza García, Nuevo León.
Corresponding author: Villarreal-Garza Cynthia; E-mail address: cynthiavg@gmail.com
Address: Av. San Fernando No.22 Col. Sección XVI, Tlalpan, 14080, Mexico City.
1. lizettegalvezh@gmail.com. Dirección postal misma que corresponsal; 2. lfonate@gmail.com, Dirección postal misma que corresponsal; 3. alejandromohar@gmail.com Dirección postal misma que corresponsal; 4. Allison.Boyes@newcastle.edu.au Dirección postal: HMRI Building, Lot 1 Kookaburra Circuit, New Lambton Heights, NSW 2305; 5. vero.psic94@gmail.com Dirección postal misma que corresponsal; 6. Corresponsal: cynthiavg@gmail.com Dirección postal: Av. San Fernando No.22 Col. Sección XVI. Ciudad de México. Tlalpan. CP. 14080

El cáncer de mama (CaMa) es un significativo problema de salud pública en México. La comprensión sobre la satisfacción de necesidades es esencial para guiar el apoyo en la atención y mejorar la calidad de vida de los pacientes. La herramienta más comprensiva para evaluar las necesidades, es la encuesta de necesidades de apoyo en la atención, forma corta de 34 reactivos (SCNS-SF34, por sus siglas en inglés). Su validez y confiabilidad se han establecido robustamente en varios idiomas. Sin embargo, no existen estudios que se enfoquen en las características específicas del proceso de adaptación cultural en pacientes con CaMa. El objetivo fue describir y analizar el proceso de adaptación cultural de SCNS-SF34 en pacientes mexicanas con CaMa, a través de un estudio piloto. Este proceso se llevó a cabo a través de un proceso estandarizado de traducción y retrotraducción por expertos en ambos idiomas. Se piloteo a 21 pacientes con el diagnóstico. Los resultados mostraron que una adaptación cultural apropiada de la SCNS-SF34 requiere ajustes literales y socioculturales; también resalta la importancia de una metodología rigurosa que tome en cuenta las condiciones culturales, conceptuales, lingüísticas y métricas del instrumento.

Palabras clave: Evaluación de necesidades; Cáncer de mama; SCNS-SF34; Prueba psicológica; Psicometría.

INTRODUCTION

Breast cancer (BC) is the leading cause of cancer death among women. In Mexico, the yearly incidence rate estimated for BC is about 204.44 per 100,000 cases, with an estimated mortality of 14.2% (Ferlay et al., 2012).

One of the most studied challenges in women with BC has been related to their needs assessment, that is, a direct measure of the gap between patients' experience and their expectations. There is evidence that women with BC perceive different types of unmet needs (Fiszer, Dolbeault, Sultan, & Bredart, 2014; Li et al., 2013). Particularly, they have considered the psychological and informational domains as the most important ones, e.g., "fear of cancer returning" and the "uncertainty about the future" (Fiszer et al., 2014). These unmet needs might contribute to morbidity and difficulties in their long-term adaptation to everyday life (Cleeland, 2007; Costanzo, Lutgendorf, Mattes, Robinson, Tewfik & Roman, 2007; Janz et al., 2007).

The Supportive Care Needs Survey Short Form-34 (SCNS-SF34) was developed to assess needs perception in people with cancer (Bredart et al., 2012). Likewise, the SCNS-SF34 has been identified as one of the most comprehensive tools designed to assess all types of cancer patients supportive care needs (Harrison et al., 2009). The SCNS-SF34 has been translated into numerous other languages and validated, with cancer patients in general, confirming its psychometrically robust properties: Spanish [in Mexico] (Doubova, Aguirre-Hernandez, Gutierrez-de la Barrera, Infante-Castaneda, & Perez-Cuevas, 2015), Italian (Zeneli et al., 2015) and German (Lehmann, Koch, & Mehnert, 2012). Particularly for BC, it has also been validated in Japanese (Okuyama et al., 2009), French (Bredart et al., 2012) and Chinese (Au et al., 2011).

However, there are no studies related to the SCNS-SF34, focused on the particular process of cultural adaptation of Mexican women with BC.

Such a report, dedicated to the adaptation into Spanish of the SCNS-SF34, is a necessary precursor for its validation.

It has been suggested that the measurement tools developed for a specific culture require a precise cultural adaptation, in order to be applicable to other cultures (Pilatti, Godoy, & Brussino, 2012). Cultural adaptation involves more than a simple translation from the original language. Failure to undertake this process accurately, before administering a measure in other cultures, may compromise the study findings and their interpretation (Mora-Ríos, Bautista-Aguilar, Natera, & Petersen, 2013).

The objective of this study was to describe the process of the cultural adaptation of the SCNS-SF34 in Mexican women with BC, emphasizing the cultural differences.

METHODS

Participants

The forward-translation judges were native Spanish speakers from Mexico, fluent in English language, with at least two years of residence in English speaking countries, including more than seven years of experience in their work. The back-translation judges were native English speakers, residing in Mexico for more than five years and also fluent in Spanish language.

The coordinators had experience in the study of measurement tools, in translation and adaptation procedures and in the treatment of patients with BC.

The eligible patients were consecutive women with BC diagnosis, older than 18 years, and treated at the Instituto Nacional de Cancerología (INCan), in Mexico City. The exclusion criteria included being unable to understand Spanish or refusal to participate.

Twenty-one women with BC were invited to this study from

June to August 2015, and all of them accepted to participate. Mean age was 46 years, with a range from 31 to 61 years. Table 1 shows the sociodemographic and clinic characteristics of the sample. In summary, seven of these women were married and nine were unmarried; seven were housewives, and six patients reported being day laborers; five concluded elementary school, five achieved high school, and five women had a bachelor's degree. The monthly income of most of their families ranged from $183 to $366 US dollars. The most frequent treatment received was the combination of surgery, chemotherapy, radiotherapy and endocrine therapy.

Table 1
Demographic and clinical characteristics of the pilot group

N=21		Mean	SD
Age (Years)		46.10	14.77
		Number	(%)
Marital status	Single (separated, divorced)	12	(57.14)
	Married (Cohabitating)	9	(33.3)
Occupation	Student	2	(9.5)
	Housewife	8	(38.1)
	Day laborer	6	(28.6)
	Unemployed	5	(23.80)
Education	Primary school	5	(23.8)
	Secondary school	3	(14.3)
	High school (including technician)	8	(38.1)
	Bachelor´s Degree	5	(23.8)
Monthly income (dls)	0-183	8	(38.1)
	183.06-366	7	(33.3)
	366.06-854	6	(28.6)
TNM clinical stages	Not staged yet	6	(28.6)
	I	4	(19)
	II	5	(23.8)
	III	4	(19)
Treatment*	Surgery	12	(4.8)
	Chemotherapy	14	(14.3)
	Radiotherapy	8	(38.1)
	Hormonal Therapy	8	(38.1)
	Others	6	(28.6)

Note: The monthly income is in USA dollar with value of 16.39 Mexican Pesos.
*Multiple responses are allowed

Instrument

Supportive care needs Survey-Short Form 34 (SCNS-SF34). Measures patients' perceptions of supportive care needs across the following five domains: a) psychological, b) health system & information, c) physical & daily living, d) patient care & support, and e) sexuality.

For each of the 34 items, patients indicate their need for help over the past month as a result of having cancer. The five point Likert scale has the following response options: 1=no need, not applicable; 2=no need, satisfied; 3=low need; 4=moderate need; and 5=high need. Standardized Likert summated scores were used to calculate domain scores ranging from 0 to 100, to allow comparison between subscales. A higher score represents higher levels of unmet need. The original validation study found that the five factors accounted for 72.1% of the total variance, and the internal reliability coefficients exceeded 0.8 for all domains (Boyes, Girgis, & Lecathelinais, 2009).

Procedure

Translation and Adaptation Process

The cultural adaptation was performed according to the process outlined in the manual "EORTC Quality of life group, translation procedure" (Cull et al., 2002).

First, two translators from English to Spanish (called forward translation judges) followed the instructions to validate the construct and content of the instrument. The target population was taken into account. The coordinators compared these forward translations to determine which items of the text had similar or different translations. If the translations showed large differences, both coordinators decided which text would be more accurate or they would merge them into one version. This is how we obtained the Integrated Spanish Version 1 of the survey.

Subsequently, the other two judges translated the instrument backwards from Spanish into English. With this second version, the coordinators repeated the procedure previously described. The differences between every translation were compared and modified accordingly. The results of these comparisons provide us with the Integrated Spanish Version 2 (the original sense of the items was maintained). This was the version that we applied to the pilot sample.

The pilot phase was carried out after obtaining the approval and consent of the Ethics and Research Review Board of the INCan. BC patients were invited to participate in this study (privately). Before answering the survey, the objective of the study was explained to the patients and the data confidentiality guaranteed.

After accepting to participate, women were asked to sign an informed consent document and they received a copy. Due to the low literacy in Mexican patients (Doubova et al., 2015), a face-to-face interview was done with the consenting participants, which included an oral questionnaire administered by trained and experienced research assistants to maximize standardization.

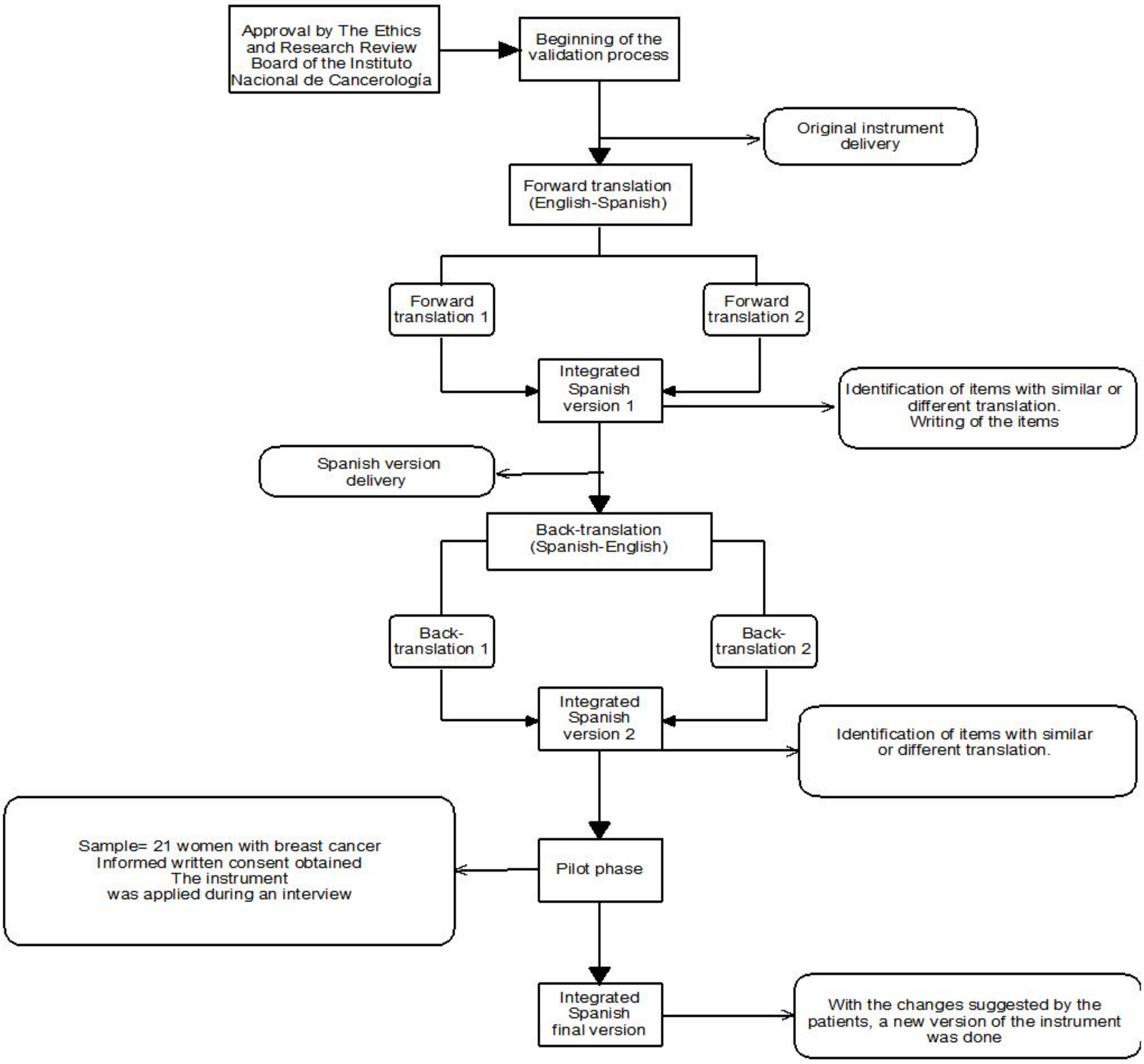

Figure 1. Flow chart of the translation and cultural adaptation process of SCNS-SF34 in Mexican women with breast cancer.

Data Collection

The research assistants interviewed the patients to corroborate if the items were clear and understandable or if they produce discomfort caused by offensive expressions. The final version of the instrument was the result of taking into account changes in the wording of several items that are suggested by the patients.

Data Analysis

The findings were ordered to show the changes done with the first translation and with the final version. The resulting data were classified in terms of a) number of changes, b) reasons for changes (e.g., syntax, coincidence between translators, patient's suggestions, common language in Mexico , communicative clarity and conciseness) and c) type of change (e.g., literal translation, substitution or word removal and semantic inclusion).

Particularly, for the final version, we analyzed which items were clear, understandable and acceptable (conceptualized as comfortable and non-offensive) by the patients (Manson, 1997). Besides, all changes in the items were analyzed using: a) item format, b) grammar and writing, and c) cultural adaptations (Muniz, Elosua, Hambleton, & International Test, 2013).

RESULTS

Analysis of changes to the final version

On the first translation: 17 items had a literal translation, seven had word substitutions and word removals, and 10 items were not changed.

The changes of the final version required the inclusion of semantic resources (Table 2 and 3). For instance: a) we did not find an equivalent in Spanish (Mexico) for certain grammatical structures in English; e.g., “sexual feeling” was adapted to “deseo sexual” (item 15), and “work around the home” (item 4) was changed to “que hacer de la casa”; b) when the word in English had only one meaning (in a medical context), but it could literally have more than one in Spanish, e.g., “results” could mean in Spanish either general consequences or from medical issues (in item 10). Likewise, “learning to feel in control of your situation” (item 12), the word “situation” caused confusion with Mexican patients, because a literal translation to Spanish was understood as an “issue” or “place”, “position” or “condition”. Additionally, other confusing words were modified: we used the Spanish definition of those words instead of their literal translation: e.g., “uncertainty” (in item 11) was adapted to Spanish as “Do not know what is going to happen”.

Finally, a literal translation to Spanish of the word “unwell” (item 3) might involve “just feeling not well”; however, we translated it as a general physical discomfort (Table 3 shows in detail these changes).

The format of the items and their length and the alternatives of answers were not changed. The use of bold words was identical in both versions; as well as the structure, design, and graphics. The order of the statements and the punctuation was not modified and every item was adjusted according to female patients.

Most of our patients indicated that they felt comfortable with every item; however, 12 items were pointed out as difficult to comprehend.

DISCUSSION

The process for the adaptation of the Mexican version of the SNCS-34 for women with BC was rigorous, and it was performed based on standardized procedures. Two strategies were used to achieve this objective: the first one prioritized the similarities with the original language (English) and the second one aimed to improve its understanding by our patients by means of applying a cultural adaptation.

The adaptation of this survey required that the items wording was congruent with the Mexican cultural characteristics and their everyday language. To achieve it, we needed to use substitution, omission, and inclusion of words or phrases in Spanish (to preserve the definition of the construct, the goal of the instrument and the meaning of the domains and items) (Cull et al., 2002; Muñiz et al., 2013).

It is relevant that many patients suggested a reduction in the complexity of the wording of the items (e.g., changing abstract words). These suggestions might be the result of a low level of health literacy among Mexican population, which has been previously reported by the US Survey data in the National Assessment of Adult Literacy (US Department of Health and Human Services, 2008). This level of health literacy was defined as basic or below basic compared to non-Hispanic blacks and non-Hispanic whites. However, it is possible that the results can be different if compared to the average Mexican population (they included just Mexican immigrants living in US). These studies emphasize the importance of considering the level of health literacy for a cultural adaptation of SCNS-SF34 (Lam et al., 2011; Zeneli et al., 2015).

Two similar studies have been conducted to test the linguistic and cultural validity of SCNS-SF34, for Italian and French versions (Bredart et al., 2012; Zeneli et al., 2015;). In the present study, differences between the French and Italian versions were found when the perception of acceptability was taken into account.

The Mexican sample indicated that all the items were acceptable. In contrast, the Italian study described that one patient indicated that item 14 (“feelings about death and dying”) was a distressing concept, and other patient felt that item 15 (“change in sexual desires”) and 16 (“change in sexual relations”) were embarrassing and unacceptable. The French study obtained missing values ranging from 7.5% to 12% of the items related to sexual needs and also for item 28: “whether cancer is under control or diminishing”.

The responses about acceptability of the Mexican sample could be because the patients may be convinced that they must obey or agree with the doctors and health personnel, and moreover, that they must be a good patient, being a compliant patient (Newman, 2000).

The other reason for these inconsistencies among studies could be related to the level of unmet needs of the BC Mexican women, perhaps they accept sensitive issues in order to solve them.

The sample size for the pilot phase could be a limitation in this study. However, it was similar to the size gathered by the French study in its pilot test phase (Bredart et al., 2012). Moreover, the results of this study are consistent with the level of clarity, understanding, and significance found in the Italian and French versions.

This survey is now available for its use, and a construct validation study is currently being performed on a larger sample of Mexican women with BC. Further research should be conducted to examine the influence of health literacy in a cultural adaptation process for these types of surveys.

In conclusion, this study is the first detailed analysis of a cultural adaptation of the SCNS-SF34 aimed to Mexican BC patients. It highlights the importance of following a methodology that takes into account sociocultural, conceptual, linguistic and metric properties. This analysis will support the understanding of the supportive care needs in developing countries such as Mexico, where this information is very limited (Reynoso, Alazraki, Gonzalez-Maraña, Alvarado, & Pulido, 2008).

Table 2
Causes for Item Change

Cause	First Translation		Final Version	
	Number of changes (per Item)	Example of changed item	Number of changes (Words, phrases)	Example of changed item (Final phase)
Syntax	1	"Haberle proporcionado explicaciones de aquellas pruebas de las que quisiera explicaciones"	11	"Que el personal del hospital reconozca y muestre sensibilidad hacia tus sentimientos"
Original meaning	15	"Cambio en sentimientos sexuales"	5	"Tener a alguien del personal del hospital con quien puedas hablar sobre todos los aspectos de tu condición, tratamiento y seguimiento"
Redundancy	2	"El personal del hospital reconoce y muestra sensibilidad hacia sus sentimientos"	2	"Que te informen acerca de las cosas que puedes hacer para ayudarte a ti mismo (a) a mejorar"
Both translators coincided with writing	9	"Aprender a sentirse en control de su situación"		
Patients´ suggestions			14	"No saber qué va a pasar"
More frequently used in Spanish	6	"Confirmación por el equipo médico de que la manera en la que usted se siente es normal"		
Communicative clarity			1	"Tener acceso a profesionales (psicólogo, trabajador social, consejero, enfermera especialista) si tú, tu familia o amigos lo necesitan"
Conciseness		"Que te informen sobre relaciones sexuales"	1	
Total	33		34	

Table 3
All item modifications SCNS-SF34: original (English) to Spanish

Item	Original Version	Final Spanish Version
1	Pain	Dolor
2	Lack of energy/tiredness	Falta de energía/cansancio
3	Feeling unwell a lot of the time	Sensación de malestar una gran parte del tiempo
4	Work around the home	Quehacer de la casa
5	Not being able to do the things you used to do	No ser capaz de hacer las cosas que hacías
6	Anxiety	Ansiedad
7	Feeling down or depressed	Sentirte triste o deprimido (a)
8	Feelings of sadness	Sentimiento de tristeza
9	Fears about the cancer spreading	Miedo de que el cáncer se extienda
10	Worry that the results of treatment are beyond your control	Preocupación de que no puedas controlar los resultados del tratamiento
11	Uncertainty about the future	No saber qué va a pasar
12	Learning to feel in control of your situation	Aprender a sentirte en control de lo que pasa
13	Keeping a positive outlook	Mantener una visión positiva

Table 3 *Continued*

Item	Original Version	Final Spanish Version
14	Feelings about death and dying	Sentimientos acerca de la muerte y morir
15	Changes in sexual feelings	Cambio en el deseo sexual
16	Changes in your sexual relationships	Cambio en tus relaciones sexuales
17	Concerns about the worries of those close to you	Intranquilidad por las preocupaciones de familia o amigos
18	More choice about which cancer specialists you see	Tener más opciones para consultar especialistas en cáncer
19	More choice about which hospital you attend	Tener más opciones de hospitales en donde atenderte
20	Reassurance by medical staff that the way you feel is normal	Que los médicos confirmen que tus molestias son normales
21	Hospital staff attending promptly to your physical needs	Que el personal del hospital atienda rápidamente tus necesidades físicas
22	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	Que el personal del hospital reconozca y muestre sensibilidad hacia tus sentimientos
23	Being given written information about the important aspects of your care	Que te proporcionen información escrita sobre aspectos importantes de tu cuidado
24	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	Que te proporcionen información (escrita, dibujos o diagramas) sobre aspectos del manejo en casa de tu enfermedad y efectos colaterales
25	Being given explanations of those tests for which you would like explanations	Que te proporcionen explicaciones sobre estudios de los que tienes duda
26	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	Que te informen adecuadamente acerca de los beneficios y efectos secundarios de los tratamientos antes de que elijas recibirlos
27	Being informed about your test results as soon as feasible	Que te informen acerca de los resultados de tus estudios lo antes posible
28	Being informed about cancer which is under control or diminishing (that is, remission)	Que te informen acerca de que el cáncer está bajo control o disminuyendo (esto es, remisión)
29	Being informed about things you can do to help yourself to get well	Que te informen acerca de las cosas que puedes hacer para ayudarte a ti mismo (a) a mejorar
30	Having access to professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if you, family or friends need it	Tener acceso a profesionales (psicólogo, trabajador social, consejero, enfermera especialista) si tú, tu familia o amigos lo necesitan
31	To be given information about sexual relationships	Que te informen sobre relaciones sexuales
32	Being treated like a person not just another case	Ser tratado (a) como una persona y no sólo como otro caso
33	Being treated in a hospital or clinic that is as physically pleasant as possible	Que las instalaciones del hospital o clínica sean lo más agradable que se pueda
34	Having one member of hospital staff with whom you can talk to about all aspects of you condition, treatment and follow-up	Tener a alguien del personal del hospital con quien puedas hablar sobre todos los aspectos de tu condición, tratamiento y seguimiento

Furthermore, in this cultural context, these results reveal that the simplest version allows more patients to be evaluated by this tool. Then, the use of this Mexican version for patients with BC would guarantee the possibility of comparing our results with those obtained in other countries.

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