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## Cultural adaptation of a supportive care needs measure for Hispanic men cancer survivors

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### Abstract

**Objective**—Research with ethnic minority populations requires instrumentation that is cultural and linguistically relevant. The aim of this study was to translate and culturally adapt the Cancer Survivor Unmet Needs (CaSUN) measure, into Spanish.

**Methods**—We describe the iterative, community-engaged consensus-building approaches used to adapt the instrument for Hispanic male cancer survivors. We used an exploratory sequential mixed method study design. Methods included: translation and back-translation, focus groups with cancer survivors (n=18) and providers (n=5), use of cognitive interview techniques to evaluate the comprehension and acceptability of the adapted instrument with survivors (n=12), ongoing input from the project's community advisory board, and preliminary psychometric analysis (n=84).

**Results**—The process emphasized conceptual, content, semantic, and technical equivalence. Combining qualitative and quantitative approaches offered a rigorous, systematic, and contextual approach to translation alone and supports the cultural adaptation of this measure in a purposeful and relevant manner.

**Conclusion**—Our findings highlight the importance of going beyond translation when adapting measures for cross-cultural populations and illustrate the importance of taking culture, literacy and language into consideration.

## Keywords

cultural adaptation; mixed methods; measurement development; cross-cultural; cancer; oncology

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## Background

The number of cancer survivors is expected to continue to increase and will reach an estimated 18 million in the coming decade.<sup>1</sup> As more people survive cancer, there is recognition of the supportive care needs of this growing population that extend well beyond the treatment phase.<sup>2</sup> This study represents one of the first systematic attempts to culturally adapt a validated measure to assess supportive care needs among Hispanic male cancer survivors (HMCS), a growing but vastly understudied group in the cancer survivorship literature. The purpose of this paper is to inform survivorship research and describe the iterative processes that were used to translate and culturally adapt the Cancer Survivor Unmet Needs measure (CaSUN). Combining qualitative and quantitative approaches offered a rigorous, systematic, and contextual approach to translation alone and supports the cultural adaptation of this measure in a purposeful and relevant manner. We describe the ten step process that incorporated both qualitative and quantitative approaches and discuss lessons learned.

Increasing awareness of the psychosocial impact of cancer has resulted in attempts to more broadly identify individual needs in order to improve supportive care services, especially for underserved and minority cancer survivors.<sup>3–5</sup> While several English-language cancer-related supportive care needs instruments exist, none have been culturally adapted for, or validated among Hispanic Spanish-speaking cancer survivors (herein defined as those who have completed initial treatment).

The majority of cancer related needs assessment measures were developed for cancer patients irrespective of treatment or disease status (e.g., the Supportive Care Needs Survey,<sup>6,7</sup> but do not specifically focus on the survivorship phase, as many of the items used assess medical care needs and may be more relevant to those in treatment.<sup>8–10</sup> However, the CaSUN was specifically developed to assess the supportive care needs of cancer survivors and is more appropriate for addressing demands of this phase of the disease trajectory.<sup>10</sup> The CaSUN covers the following domains: existential survivorship, comprehensive care, information, Quality of Life and relationships. It also includes six positive change items and has been widely used across a variety of cancer types (e.g., hematological, testicular, and other gynecological cancers).<sup>11–14</sup> However, the CaSUN,<sup>9</sup> was developed in Australia, primarily with a sample of breast cancer survivors and thus we felt it may not reflect the needs and cultural experience of HMCS.

While many domains relating to the cancer experience may be universal, people experience them differently depending on their “worldview.”<sup>15,16</sup> Thus, the rationale for the translation and cultural adaptation of the CaSUN measure is guided by evidence that research strategies and assessments are more effective when they are compatible with the patient or audience’s culture and experiences, and include items that are conceptually relevant and reflective of the issues encountered.<sup>17–21</sup>

Survivorship research with ethnically diverse populations requires instrumentation that is sensitive to cultural and contextual variations.<sup>22–26</sup> Attaining cultural sensitivity in instrumentation requires translations into languages other than English.<sup>27</sup> Cross-cultural research has shown that translation alone is not sufficient to obtain cross-cultural equivalence of research instruments.<sup>21,28,29</sup>

Differences in the conceptualization and operationalization of health-related concepts underscore the importance of examining cross-cultural equivalence when adapting and translating instruments.<sup>30</sup> When culturally adapting instruments for Hispanics, it is imperative that we take cultural, linguistic and contextual issues into account, and are inclusive of the issues that are significant to those for whom the instrument is being adapted. Many instruments and measures are developed without consideration for the subtle linguistic and cultural variations within ethnic groups which may affect the interpretation and understanding of specific items. It is important to keep in mind that Hispanics are a diverse and heterogeneous group and consequently, there is need to delineate, how terms and concepts are understood, expressed and experienced in this population.

## Methods

We used an exploratory sequential mixed method study design appropriate for measurement development.<sup>31</sup> We employed a series of iterative, systematic and group consensus-building approaches to translate and culturally adapt the previously validated CaSUN measure into Spanish for HMCS. The cyclical process of measurement adaptation and validation underscores the value of mixed methods research, where qualitative and quantitative approaches are complementary<sup>32</sup> and are inclusive of both emic and etic perspectives.<sup>33,34</sup> The emic perspective starts with the descriptions and concepts from within the culture (insider or inductive) and seeks to understand the meaning of that which is being studied from within the group's cultural framework.<sup>27,28</sup> The etic perspective includes how the concepts are viewed and interpreted by the outsider or deductive perspective, in this case the perspectives of researchers, providers and scientific community.<sup>35</sup>

We drew from the Cultural Equivalency Model for Translating and Adapting Instruments<sup>22</sup> and focused on the conceptual (does the content relate to constructs in the culture?), content (is the content of each item relevant to the population under study?), semantic (is there similar meaning of items in each culture?), and technical equivalence (this includes keeping a similar layout, format, and coding system).<sup>36</sup> In adapting a measure for a cross-cultural audience it was important that the research team, in part, reflect the diversity of the Hispanic population. Thus, the research team consisted of Cuban, Puerto Rican, Colombian, and Dominican bilingual and native Spanish speakers. The study took place in west central Florida where Latinos are the largest and fastest growing ethnic group, constituting 22% (n=263,156) of the population in Hillsborough County, 24% (n=259,240) in Orange County, and 41% (103,608) in Osceola County.<sup>37</sup>

## Sample and Recruitment

A purposive a sampling strategy, which is an appropriate for focus groups, piloting/ pretesting questionnaires and exploratory research, was used.<sup>38</sup> Participants were recruited

through established relationships with community organizations that serve cancer survivors in west central Florida that work with Latinos from various nationalities (e.g., Cuban, Mexican, Puerto Rican, Colombia etc.). We used flyers and word of mouth to recruit participants from community organizations. HMCS were also recruited using the cancer registry at a local cancer center. HMCS, had to self-identify as Hispanic/Latino, be able to communicate in Spanish, be between 18 and 75 years old, be within 5 years from diagnosis, and have completed initial cancer treatment. Our goal was to include cancer survivors from diverse backgrounds (e.g., countries of origin, educational attainment, SES etc.) and cancer types (e.g., prostate, colon, bladder etc.) to ensure that we captured multiple perspectives. The study was approved by the University of South Florida IRB. The steps and methodology followed to translate and adapt the CaSUN are illustrated in Figure 1 and are described below.

### **Step 1: Creation of the Cultural Adaptation Community Advisory Board (CA-CAB)**

Drawing from the principles of community-engaged research<sup>39,40</sup> and building on established community partnerships with cancer care and community-based organizations that serve Hispanic cancer survivors, our first step was to form a Cultural Adaptation Community Advisory Board (CA-CAB). The purpose of the CA-CAB was to provide ongoing feedback and subject expertise throughout the translation and adaptation process, ensuring the creation of a relevant, useful instrument to accurately capture the needs of the priority population. The seven-member CA-CAB consisted of cancer survivors, a cancer survivorship researcher, survivor advocates, a psychiatrist, a mental health counselor and a cancer survivor navigator. Members were bilingual, whose mother tongue was Spanish, knowledgeable about the constructs being assessed, and represented five different Spanish-speaking countries (Cuba, Puerto Rico, Colombia, Ecuador, and Venezuela). Members of the CA-CAB also had extensive experience working with diverse Hispanic groups including US born, immigrant and migrant farmworkers who, in our area, are primarily of Mexican decent. The members served in an advisory role where they provided information, guidance, and ongoing input throughout the adaptation process through in person meetings and via conference calls/email as needed. Any changes made to the measure by the researchers were discussed with the CA-CAB. The CA-CAB was slated to meet on a quarterly basis over the two-year project; however, in response to project needs they met more frequently during the first year and less frequently in year two. The members of the CA-CAB were provided an honorarium for their time.

### **Step 2: Translation of the CaSUN**

We drew from the Brislin Model<sup>34</sup> to guide the translation of the CaSUN from English to Spanish. First, a bilingual member of the research team, whose primary language is Spanish, forward translated the CaSUN from English into Spanish. Subsequently, another bilingual member of the research team blindly back translated the Spanish version into English. The two translators along with the Principal Investigator met to discuss any ambiguities and discrepancies identified through the translation and back-translation processes. At this stage, careful consideration was made to minimize modifications to the items and format/layout of the original version of the CaSUN.

### Step 3: CA-CAB review of the translated CaSUN

CA-CAB members reviewed the translated CaSUN (hereinafter referred to as “the Spanish CaSUN” (S-CaSUN) and discussed alternative words and synonyms for words or concepts that were difficult to translate. Consideration was given to the original meaning of the items. However, some items were modified to facilitate comprehension while maintaining the intended meaning. Careful attention was given to the literacy level of the translated items. When there were regional variations for a Spanish term, the members came to a consensus on the term that would be the most appropriate cross-culturally. During this step, CA-CAB members provided feedback and helped develop the interview guides that would be used in Step 4.

### Step 4: Obtain input from emic and etic perspectives

Focus groups, frequently used in instrument development and refinement<sup>41</sup>, were conducted with HMCS (three focus groups, n=18) to: 1) better understand the supportive care needs of Hispanic men from the emic perspective, and 2) to assess the cultural relevance of the domains of the S-CaSUN (from Step 3). To gain the etic perspective, we conducted interviews with providers (n=5). Providers included health professionals (e.g., social workers, oncologists, nurses) with experience working with/or providing care to HMCS. The focus group and interview data were transcribed verbatim, coded and analyzed using applied thematic analysis techniques<sup>4</sup>. Participants described the need for the following: culturally sensitive cancer care such as having the time to build *confianza* (trust) with providers, and better communication with providers, more cancer treatment-related information and comprehensive survivorship care, support, to connect with other cancer survivors and to negotiate changing gender role expectations and still provide for their family. The methods and results of the focus groups and interviews are reported elsewhere.<sup>4</sup> The findings from Step 4 were presented to the CA-CAB and were used by the CA-CAB as the basis for the revisions to the S-CaSUN in Step 5.

### Step 5: Infuse Findings from Step 4 and Make Needed Revisions

The CA-CAB, along with the research team compared the translated and the original versions of the measure to the findings from focus groups and interviews. The wording of items evaluated by the HMCS and providers and considered difficult to comprehend were modified/adapted to ensure understandability, while maintaining the intended meaning. The CA-CAB also revised existing items to simplify the language, paid special attention to the literacy level of the items and attempted to use words common across Hispanic subgroups. The CA-CAB assisted with the formulation of additional items in response to needs that were identified in Step 4 that were not included in the original CaSUN. Once the changes had been made the S-CaSUN was ready to be field tested using cognitive interviews as described in Step 6.

### Step 6: Conduct a Series of Cognitive Interviews

Cognitive interview techniques are a qualitative method explicitly designed to examine survey questions and assess whether they fulfill their purpose.<sup>42</sup> They were used to systematically evaluate how the items in the S-CaSUN were understood by the HMCS.<sup>26,43</sup>

Because of the formative nature of this iterative process, only small samples at each iterative point were needed.<sup>42</sup> We conducted three sets of one-on-one interviews with a total of 12 participants using think-aloud and probing questions.<sup>28</sup>

The interviews were conducted by a pair of bilingual research members. One served as the lead interviewer who coordinated and conducted the cognitive interviews. The second served as a note taker who took detailed field notes about the interview procedures, participants' comments, suggestions and reactions to the S-CASUN. The cognitive interviews were audio taped and took place at the participants' homes or another private setting. After each set of iterations, the responses and detailed field notes from the cognitive interviews were tabulated and coded using a modified version of the coding scheme used by Willis and Zahnd.<sup>25</sup> We used a qualitative approach to analyze the cognitive interview data by looking at patterns and recurring themes.

The first set of cognitive interviews (n=5) focused on comprehension, translation, and the format of the S-CaSUN. Participants were asked to read the S-CaSUN and to share their reaction about the measure in general, as well as their impressions about specific aspects of the measure, including the domains, section headers, response alternatives, and questions items. Participants were asked a series of pre-scripted questions such as "What do you think this question is trying to ask you?" "Can you repeat the question in your own words?" We observed participants' response to the questions and documented pauses, hesitancy and other nonverbal cues. Some participants wrote their suggested edits on the questionnaire.

The focus of the second set of cognitive interviews (n=4) centered on the linguistic acceptability and appropriateness of the S-CaSUN. For example, we asked participants, "Do you think others like you would feel comfortable answering these questions? What other words can we use?" Participants were probed about the changes made after the first iteration. Lastly, the third iteration (n=3) focused on cultural acceptability, as well as the feasibility of administering the S-CaSUN and asked questions such as "Is the length of this interview right for you?"

### **Step 7: Revision of S-CaSUN with CAB Input**

The research team debriefed after each set of cognitive interviews and made the needed revisions and modifications before the next round of iterations. Problematic items were revised and suggestions for additional items and clarification were incorporated. The results of the cognitive interviews were then presented to the CA-CAB for their review and input before moving on to the next step.

### **Step 8: Back Translation and Review of the S-CaSUN**

After step seven, we had a solid draft of the S-CaSUN. At this point it was translated back to English. The culturally adapted S-CaSUN and the translated English copy were presented to the CA-CAB. The CA-CAB along with the Principal Investigator met to discuss any discrepancies in meaning/concepts. Minor revisions to the English translation were made. Once edits were made we had a final draft culturally adapted S-CaSUN in both Spanish and English. Furthermore, the S-CaSUN was reviewed by an oncology nurse, expert in measurement and instrument development (SM), as well as by an established researcher



with expertise in the areas of health disparities, men's health, and cancer survivorship (CG). The S-CaSUN was then ready for the preliminary psychometric assessment.

### **Step 9: Field Testing/Preliminary Psychometric Assessment of the Culturally Adapted Measure**

We assessed the psychometric properties of the S-CaSUN to provide initial evidence of its validity and reliability.<sup>44</sup> A sample size of 84 participants was determined to provide 80% power to detect a medium effect size of .31, at the two-sided 0.05, significance level.<sup>45</sup> This sample size was derived through G\*Power 3 statistical power analysis program.<sup>46</sup> Construct validity of the S-CaSUN was established by moderate correlation with the HADS-A ( $r = 0.60, P < 0.001$ ), HADS-D ( $r = 0.55, P < 0.001$ ), and the FACT-GP ( $r = -0.61, P < 0.001$ ).<sup>47,48,49</sup> Psychometric properties, including internal consistency (Cronbach's alpha = .96) and test-retest reliability ( $r = .80$ ), were strong. The results from the validity and reliability assessment of the S-CaSUN indicate psychometric properties that are similar or better than those of the original CaSUN. After administering the S-CaSUN, we asked participants four open-ended questions to assess the culturally adapted S-CaSUN in terms of relevance, comprehensiveness, acceptability and to identify additional areas of need. We also took detailed field notes about the flow, as well as other unsolicited comments from the respondents.

## **Results**

Table 1 presents the demographics of the participants that informed the adaptation of the CaSUN, including cancer care providers, HMCS from the focus groups, cognitive interviews and the members of the CA-CAB. The results of the cultural adaptation of the CaSUN are presented in terms of the semantic, content, and technical equivalence,<sup>28</sup> illustrative examples are provided in Table 2, 3 and 4. Study participants received an executive summary of the study results and were invited to a *charla* (community talk) where findings were presented in Spanish.

### **Content equivalence**

One of the overarching issues with the cultural adaptation of the original CaSUN was the translation of the concept of “unmet needs.” This was problematic because the concept of “unmet need” does not exist in Spanish. In other words, there is no Spanish language equivalent for unmet need that would clearly capture the concept being measured in the original CaSUN. Thus, we needed to modify the measure to capture the needs vs. the unmet needs.

While the concept of “unmet need” was an issue, HMCS, providers and CA-CAB members found the domains of the CaSUN to be important and meaningful for cancer survivors. However, a few of the items were considered irrelevant to the experience of HMCS. See Table 2 for illustrative examples. HMCS also identified several items that were missing in the original CaSUN to capture relevant needs, such as their relationship with providers. The CA-CAB helped us create new items to capture these needs. Items perceived as irrelevant were eliminated; however, a few items (e.g., related to fertility) were kept as they were

considered by the CA-CAB to be very important for younger cancer survivors who might still like to father children. The wording of some of the items was changed to more adequately capture the needs of HMCS.

### **Semantic equivalence**

Examples of the types of translation issues we encountered through the cultural adaptation process, as well as the revisions made to address them, are listed in Table 3. We needed to use neutral Spanish that avoided colloquial terms or word phrases that could vary from country to country. This was addressed by utilizing alternative terms that were universally understood in Spanish; thus ensuring individuals from different Spanish-speaking countries could understand. In addition, the subtle connotation of certain words was viewed as problematic as the word may evoke strong emotions or influence the way in which respondents would answer. Also some of the original items were found to be too wordy, confusing, and inappropriate for respondents with low literacy levels. Using simpler words, avoiding technical terms, and shortening sentences addressed these issues.

### **Technical equivalence**

As previously stated the concept of “unmet need” did not translate into Spanish which led to major changes in the umbrella question, question headers (See Table 4) and inevitably the format of the S-CaSUN. We changed the overarching question to directly ask what participants have needed in the last month. Moreover, the CA-CAB, HMCS and providers emphasized the need to significantly change the layout and format in order to simplify the measure, and provided suggestions for modifying the format. Figure 2 shows the multiple revisions that were made to the layout, questions and response options of the instrument throughout the adaptation process. Other general formatting issues included response options, the order of items, the reporting period (e.g., within the last month – which we did not change), and the additional explanations of items to improve comprehension and clarity.

## **Discussion**

Using an iterative, community-engaged consensus-building approach we were able to adapt the CaSUN for HMCS. Moreover, our combined methodologies (e.g., qualitative and quantitative) offered a rigorous, systematic, and contextual approach to translation alone and supported the cultural adaptation of this measure in a purposeful and relevant manner. Our findings underscore the importance of going beyond translation when adapting measures for cross-cultural populations and illustrate the importance of taking culture, literacy and language into consideration

We highlight some of the complexities of the process and lessons learned through the cultural adaptation of the CaSUN. One of our greatest challenges was balancing between the emic (finding cultural equivalence) and etic (preserving the comparability of the culturally adapted S-CaSUN) with the original CaSUN.<sup>27</sup> While we were able to maintain the domains of the original CaSUN we had to modify the layout and format of the items to ensure cultural acceptability, understandability and comprehensibility of the measure. As described in previous paragraphs, there is no equivalent term for “unmet need” in Spanish, which

automatically negated the original format. In addition, HMCS, providers, and the CA-CAB found the original format confusing and felt it was too complicated, especially for individuals with low-literacy. Our decision to change the layout and format was a difficult one because it may in turn affect the culturally adapted measure's technical equivalence and comparability to the original CaSUN.<sup>22</sup> While we gave this potential issue serious consideration, at the end we decided it was necessary to make the changes so that we had a measure that was culturally and literacy relevant to HMCS. We feared not changing this would result in erroneous or meaningless responses to the S-CaSUN.

The systematic and iterative processes we used were vital and illustrate that if we had stopped at translation alone we would have missed including items that correspond to the realities and needs of Hispanic men cancer survivors. As stated by Squires et al.,<sup>50</sup> forward and back translation alone is not sufficient to produce reliable and valid translation of measures.

We also encountered the need to strike a balance between the number of culturally relevant items that needed to be added and the length of the measure. Thus, we had to compromise between the need to include new items that were derived from the focus groups and cognitive interviews, and the length of the measure.

We needed to consider literacy as part of the translation and cultural adaptation process. As we translated certain items, we found the literacy level of the translated Spanish item was higher than the original English. Thus we had to continually review and ensure that the translated items were written in simple language that was easy to understand, while still conveying the same or intended meaning. To address this, a decision was made to use shorter sentences, active instead of passive voice, and to avoid colloquial expressions.<sup>20</sup> When culturally adapting measures it is important to include individuals with a wide range of years of educational attainment to ensure comprehension across literacy levels (e.g., we had 12 HMCS who had a high school degree or less and 13 individuals with a graduate degree or higher).

The value of including both bilingual and monolingual speakers in the adaptation process was invaluable. Having both monolingual and bilingual HMCS and CA-CAB members proved beneficial since each provided a different perspective. Bilinguals understood the construct in the original language and were able to assist with translation into Spanish. Monolinguals were able to tell us if the constructs and items were relevant and understood. We encountered variations in how things were said in different Spanish speaking countries; thus, it was imperative to include participants from multiple nationalities.

The ongoing feedback of the CA-CAB was invaluable. Throughout the cultural adaptation process, the CA-CAB was instrumental in reviewing the translations of the CaSUN, modifying and creating items, as well as assisting with interpretation of findings after each step. The use of mixed methods and community-engaged approaches to culturally adapt a measure is labor intensive, costly and takes a long time. However, in light of changing population demographics such efforts are essential<sup>51</sup> if we are going to conduct psychosocial research with diverse and non-English speaking cancer patients and survivors. In spite of

existing guidelines to facilitate translatability of research instruments<sup>34</sup> many instruments have not been developed with that in mind.<sup>52</sup> Considering a research landscape that is more diverse and inclusive of multicultural populations, we need to keep the translatability and cultural adaptability in mind and consider cross-cultural equivalence and cultural adaptation of the instruments commonly used in psycho-oncology.<sup>29,30,53</sup>

## Strengths and Limitations

Study limitations are described herein. Compared to the national Hispanic population, our study included a smaller proportion of Mexicans. However, this is reflective of the Hispanic population in west central Florida where Puerto Ricans make up the largest proportion of Hispanics in the area. Nonetheless, we were still able to recruit a diverse sample of Hispanic participants with over 15 nationalities represented. In addition, the Mexican population in the area is younger in age compared to other groups in the area. Mexican men, for example, have a median age of 25.5 compared to 37.8 for Cuban men.<sup>37</sup> Another limitation of this study is the exclusion of women cancer survivors. Our decision to only include men was based on the paucity of survivorship research on the supportive care needs of Hispanic men. However, we recognize the need to have a valid and reliable tool that could also be used with Hispanic women cancer survivors. Thus, we have applied and received funding to replicate portions of this study with women, which will make the CaSUN applicable to a wider population of both men and women Hispanic cancer survivors. Finally, the relatively small sample size limited our ability to conduct additional psychometric tests. However, this sets the stage for future work as described in the next paragraph.

## Conclusion and Implications for Research/Practice

This study was designed to pilot test and provide preliminary evidence of validity and reliability of the culturally adapted measure for Hispanic men cancer survivors. Findings serve as preliminary data for a national population-based study that: 1) can support a larger diverse Hispanic (e.g., include a larger proportion of Mexican cancer survivors) sample which will facilitate researchers' ability to conduct additional psychometric tests such as confirmatory factor analysis to confirm factor structure, and 2) examine the S-CaSUN's predictive validity.

Before programs and interventions are developed to improve negative disease and treatment effects and outcomes, researchers must develop an understanding of cancer survivor needs and illness experiences. In a time of limited resources, such tools can also help to identify individuals who would most likely benefit from targeted supportive interventions. Our systematic processes underscore the importance of taking culture, literacy and language into consideration when developing/adapting instrumentation for diverse populations. As the number of Hispanic cancer survivors grows, instruments with good psychometric characteristic are needed to capture the needs of non-English speaking cancer survivors. Tools like the S-CaSUN can be used in the field of psycho-oncology to assess the unmet supportive care needs of Hispanic cancer survivors, and to identify the types of interventions and programs that could be the most beneficial. In summary, our findings inform an

evidence-based approach for the cross-cultural adaptation of validated measures and add to the sparse literature on cancer survivorship among Hispanic men.

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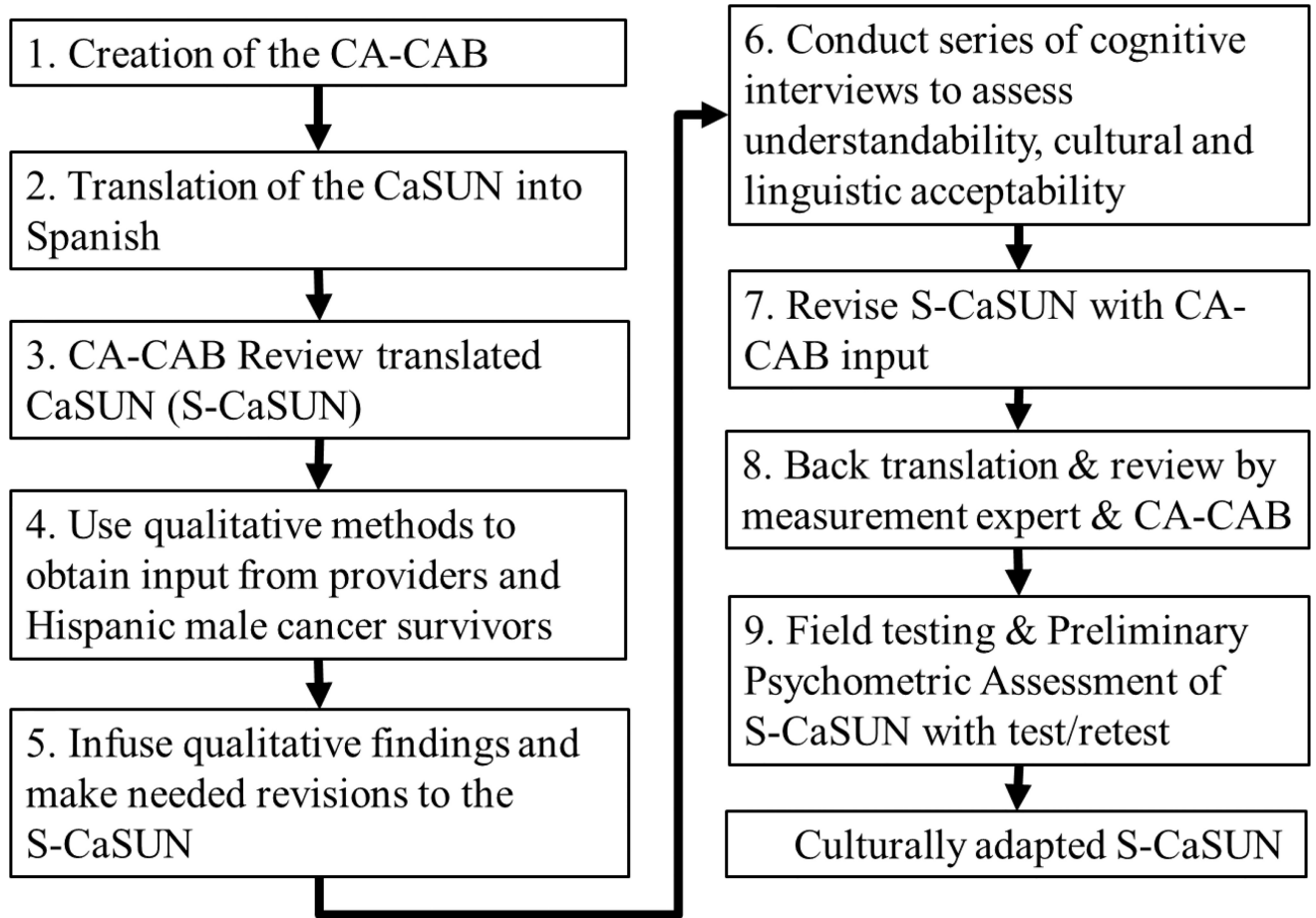
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**Figure 1.**  
Steps in the cultural adaptation process of the CaSUN



Original	In the last month...	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
		No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
	1. I need up to date information....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHAT HAVE BEEN YOUR NEEDS IN THE LAST MONTH AND HOW DO YOU RANK THEIR IMPORTANCE?						
Revision 1	During the last month I needed....	No	N/A	Little	Moderate	Very
	1. Up to date information....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHAT HAVE BEEN YOUR NEEDS IN THE LAST MONTH AND HOW DO YOU RANK THEIR IMPORTANCE?					
Revision 2	During the last month I needed....	Yes	Little	Moderate	Very
	1. Up to date information about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHAT HAVE YOU NEEDED IN THE LAST MONTH AND HOW MUCH HAVE YOU NEEDED IT?					
Final	During the last month I needed...	No	Yes, a little	Yes, more or less	Yes, a lot
	1. Up to date information about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Figure 2.**  
Format iterations

**Table 1**

Demographic characteristics

Method	HMCS			CA-CAB Ongoing input	Providers Interviews
	Focus groups n=18	Cognitive Interviews n=12	Field Testing n=84		
Male	18 (100%)	12 (100%)	84 (100%)	3 (43%)	2 (40%)
Female				4 (57%)	3 (60%)
<b>Age</b>					
<30			1 (1%)		
30-49		3 (25%)	22 (26%)	3 (43%)	3 (60%)
50-59	3 (17%)	1 (8%)	27 (32%)	1 (14%)	2 (40%)
60-69	8 (44%)	3 (25%)	27 (32%)	1 (14%)	
70-75	6 (33%)	3 (25%)	7 (8%)	2 (29%)	
Missing	1 (6%)	2 (17%)			
<b>Education</b>					
Less than high school	5 (28%)	2 (17%)	19 (23%)		
High school/Vocational	3 (17%)	2 (17%)	38 (45%)		
College/Some College	7 (39%)	4 (33%)	17 (20%)	2 (29%)	1 (20%)
Graduate level	0 (0%)	3 (25%)	10 (12%)	5 (71%)	4 (80%)
Missing	3 (17%)	1 (8%)			
<b>Language spoken</b>					
Spanish only	10 (56%)	7 (58%)	69 (82%)		
Bilingual	8 (44%)	5 (42%)	15 (18%)	7 (100%)	5 (100%)
<b>Hispanic Nationality</b>					
Argentina			1 (1%)		1 (20%)
Bolivia			1 (1%)		
Chile			1 (1%)		
Colombia	1 (6%)	3 (25%)	7 (8%)	1 (14%)	1 (20%)
Cuba	7 (39%)	1 (8%)	22 (26%)	1 (14%)	

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Method	HMCS			CA-CAB Ongoing input	Providers Interviews
	Focus groups n=18	Cognitive Interviews n=12	Field Testing n=84		
Dominican Republic	1 (6%)		5 (6%)	n=7 1 (14%)	n=5 1 (20%)
Ecuador			0		
Spain			4 (5%)		
Guatemala			1 (1%)		
El Salvador		1 (8%)	1 (1%)		
Mexico		2 (17%)	7 (8%)		
Panama		1 (8%)			
Peru	2 (11%)	2 (17%)	3 (4%)		
Puerto Rico	7 (39%)		27 (32%)	3 (43%)	1 (20%)
United States					1 (20%)
Venezuela			1 (1%)	1 (14%)	
Missing		2 (17%)	3 (4%)		
<b>Cancer Type</b>					
Prostate	6 (33%)	6 (50%)	27 (32%)	2 (29%)	NA
Lymphoid/Hematopoietic			15 (18%)		NA
Colorectal	4 (22%)		10 (12%)		NA
Digestive	1 (6%)		8 (10%)		NA
Head and Neck			7 (8%)		NA
Kidney	2 (11%)		5 (6%)		NA
Other	5 (28%)		12 (14%)		NA
Missing		6 (50%)			NA

**Table 2**

Content equivalence-related issues, illustrative examples, and solutions

Content equivalence			
Issue	Illustrative examples	Description	Revision
<b>Lack of equivalent term for concept of “unmet needs”</b>	The phrase literally translates to <i>necesidad insatisfecha</i> (unsatisfied need). Participants found this translation confusing because by definition something is needed because it is unsatisfied, and once fulfilled it is no longer a need. Thus, a <i>necesidad satisfecha</i> (met need) is also a contradiction.	The overarching question was modified to elicit participants’ needs in the past month: “what have you needed in the last month and how much have you needed it?”	Changed the measure to a needs measure vs. an unmet needs measure.
	Absence of question addressing their relationship with health care providers	Participants wanted to be treated by health care providers in a warm and personable manner. Patient-provider relationships were considered an important aspect of cancer care. Participants described this as “ <i>el trato latino</i> ”.	<u>Question added</u> : The doctors and nurses to treat me in a warmer and/or friendlier way.
	Absence of question addressing the change in family members’ roles	Hispanic men survivors mentioned struggling with changing roles within the household, such as no longer being the primary provider.	<u>Question added</u> : Help to adapt to the new role I play in my family.
<b>Irrelevant items</b>	Absence of question addressing the need for information about nutrition	Hispanic men discussed frustration that doctors do not address nutrition, and felt it is an integral part of cancer care.	<u>Question added</u> : Help to know how to eat healthy.
	Original: I need help with having a family due to fertility problems.	Various cancer survivor participants felt this question was not relevant and should be deleted	The CA-CAB felt this item would be relevant to younger cancer survivors and thus no change was made.
<b>Modified items</b>	Original: I need help to cope with others not acknowledging the impact that cancer has had on my life.	Overall, participants did not understand this question or felt the item was irrelevant to LMCS.	Item was removed.
	Original: I need emotional support to be provided for me.	Depression was discussed as a major concern, and the original question items did not address this concern directly. However, avoidance of the word “depression” was identified, as it is commonly stigmatized among Hispanic men.	<u>Final</u> Access to psychotherapy or other program that would help my mood, <i>estado de ánimo</i> .
	Majority of items in English version begin with “I need help to” (e.g., I need help to move on with my life, I need help to make my life count)	This was identified as problematic across participant groups. Repetition of <i>Necesito ayuda</i> (I need help) was identified as seeming needy, demanding, or weak/vulnerable by cancer survivor participants.	We added an umbrella question that contained <i>necesito</i> (I need) so the repetition of the term “I need” was avoided.

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**Table 3**

Semantic equivalence-related issues, illustrative examples, and solutions

Semantic equivalence			
Issue	Illustrative examples	Description	Revision
<b>Multiple meaning for same word in Spanish</b>	Original: I need local health care services that are available when I require them	Initially translated as <i>Atención médica (local) disponible</i> , but meaning of <i>local</i> is not universal among Spanish-speakers, or participants reported thinking of (local) as a place.	<i>Atención médica “cercana”</i> (nearby) <i>disponible</i> was used as an alternative translation.  Final: Health care services available nearby.
<b>Connotation of wording</b>	Original: I need to talk to others who have experienced cancer.	Common ways used in Spanish to refer to a cancer survivor include: Someone who has <i>luchado contra or batallado con</i> (fought/battled with), <i>sufrido de</i> (suffered from), and <i>han tenido</i> (have had). All carry different connotations in Spanish	<i>Han tenido</i> was chosen because it was perceived to have a neutral connotation.  Final: To talk with others who have had cancer.
<b>Translation resulted in lengthy and/or indirect questions</b>	Original: I need to feel like I am managing my health together with the medical team.	The direct translation was more complex than needed to convey the meaning of the question: <i>“Necesito sentir que estoy manejando mi salud junto con el equipo médico”</i>	Adapted item was considered a more concise/direct way to capture equivalent information. It also incorporated the needs Identified by HMCS.  Final: To feel that my opinion is important to my doctor.
<b>Complex wording</b>	Original: I need help to try to make decisions about my life in the context of uncertainty.	Simplification of wording was perceived to be more appropriate for wider range of literacy levels.	“Context of uncertainty” was changed to “times of uncertainty”  Final: Help to make decisions in times of uncertainty.

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**Table 4**

Technical equivalence-related issues, illustrative examples, and solutions

Technical equivalence		
Issue	Description	Revision and adaptation
<b>Needed to change the format due to the lack of an equivalent term in Spanish for the concept of “unmet needs”</b>	There is no Spanish language equivalent for unmet need that would clearly capture the concept being measured in the original CaSUN. The phrase literally translates to <i>necesidad insatisfecha</i> (unsatisfied need). Participants found this translation confusing because by definition something is needed because it is unsatisfied, and once fulfilled it is no longer a need. Thus, a <i>necesidad satisfecha</i> (met need) is a contradiction.	The overarching question was modified to elicit participants’ needs in the past month: “what have you needed in the last month and how much have you needed it?”
<b>Ordering of question items and response alternatives</b>	The order in which some question items were presented influenced participants’ responses to later question items. Additionally, the order of response options was unclear and confusing.	Asking certain questions first allowed participants to become familiar with the measure format and avoided biasing responses. For example, to avoid participants framing subsequent questions in the context of religion, a question item about faith / spirituality was moved to the end of the section on “positive changes”
<b>Time references/reporting period</b>	Throughout cognitive and field testing interviews participants stated that a reporting period of the past month was difficult to report and too short. Suggestions for broader reporting periods varied (e.g. since time of diagnosis, last six months, since end of treatment).  Other HMCS, although they did not critique the time period, were noticeably reporting on needs they had since diagnosis or treatment, not only from the past month.	No change in time period was made. The reporting time period of the last month was determined to best capture recent needs.  Emphasis was placed on eliciting needs during the last month by boldfacing, underlining, and enlarging the font to make it more prominent. Also, a header with the phrase “during the last month” and response options was added the measure whenever a section continued onto the next page.
<b>Response alternatives</b>	The categories used to elicit the strength of a need were initially translated as follows: <i>poco</i> (little) <i>moderado</i> (moderately), and <i>mucho</i> (a lot). Although some participants did not have any trouble distinguishing between these categories, some felt the options of poco and moderado were not easily distinguishable. Some stated that poco and moderado could go in the same column.	The final response options to identify the strength of a need are: <i>sí, poco</i> , (yes, a little), <i>sí, más o menos</i> (yes, somewhat), and <i>sí, mucho</i> (yes, a lot) in addition to <i>no</i> .
<b>Length/ Number of items in adapted measure</b>	Some participants considered the measure to be too long. HMCS acknowledged that the measure was comprehensive and helped cancer survivors reflect on/identify the many ways cancer has affected their life.	After adding missing items and removing items considered irrelevant, the adapted measure has 43 items.

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