CancerSupportSource™-Spanish: Development of a multidimensional distress screening measure for Spanish-Speaking Hispanic and Latino individuals living with cancer

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Hendershot:
None to disclose.
Our Mission

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.
Our Reach

CSC and Gilda's Club centers as well as hospital partnerships in the U.S. and around the world.

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- CSC SOUTH BAY
- CSC PASADENA
- CSC LOS ANGELES
- CSC CALIFORNIA CENTRAL COAST
- CSC SAN FRANCISCO BAY AREA
- CSC VALLEY/VENTURA/SANTA BARBARA
- CSC DELAWARE
- CSC WASHINGTON D.C.
- GC SOUTH FLORIDA
- CSC ATLANTA
- GC CHICAGO
- CSC INDIANA
- GC QUAD CITIES
- GC KENTUCKIANA
- CSC MASSACHUSETTS
- CSC GREATER ANN ARBOR
- GC GRAND RAPIDS
- GC METRO DETROIT
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- GC GREATER TORONTO
- GC SIMCOE MUSKOKA
- CSC JAPAN
- TWC TEL-AVIV
- TWC BAGHDAD

### UNIVERSITY LOCATIONS
- CSC AT UNIVERSITY OF GEORGIA
- CSC AT NORTHERN ARIZONA UNIVERSITY
- GC AT ST. AMBROSE UNIVERSITY

### OPENING IN 2023-2024
- CSC SW COLORADO
CancerSupportSource™-Spanish
Outline and Objectives

Outline
I. Project Overview
II. Screener Development
III. Screener Validation
IV. Program Implementation
V. Summary

Objectives
Workshop attendees will learn:
• Importance of distress screening in cancer care and related disparities
• Crucial steps in screener development, translation, and validation
• Utility of the CancerSupportSource™ program for assessing and addressing unmet needs in cancer
I. Project Overview
The Need

- In the US, Hispanic and Latino individuals living with cancer experience significant disparities, yet have limited access to culturally and linguistically competent distress screening and support that can improve their well-being.

The Program

- CancerSupportSource™ (CSS), a distress screening and referral program, identifies unmet needs of people with cancer and links them to resources and support.
- We developed and validated a Spanish-language version (CSS-Spanish) to better serve Hispanic and Latino communities and promote health equity.
CancerSupportSource-Spanish

Screener Summary

We created **CSS-Spanish**, a 25-item, psychometrically robust measure of distress and unmet needs.

**CSS-Spanish screens for:**

- Concerns across key areas of life
- Risk for clinically significant depression and anxiety
- Desired support and resource needs

**CSS-Spanish** is delivered via a web-based platform to support screening, referral, and follow-up.
II. Screener Development
Iterative process of review, including multiple voices, capturing various cultural backgrounds and types of expertise.

Do screener items capture the needs of diverse cultures within Hispanic and Latino communities?
CancerSupportSource-Spanish
Gold Standard Translation Process

**Preparation**
Creation and examination of content

**Forward Translation**
Translation from English to US Spanish by linguistic team

**Back Translation**
Translation from US Spanish to English by new linguistic team

**Reconciliation**
Quality manager compares translations and reconciles content to ensure conceptual equivalence between languages

**Review and Harmonization**
Additional quality control step comparing multiple versions of the translation and identifying content for further review

- Informed by World Health Organization (WHO) and Professional Society for Health Economics and Outcomes Research (ISPOR)
- Consideration for most common Spanish dialects in US (Mexican and Caribbean Spanish)
- Unique translators at each stage of the process, all native speakers or subject matter experts
Expert interview team of three individuals

- All native Spanish language speakers
- Research Analysts and Methodologists with Masters or PhDs (Public Policy, Sociology, Human Development & Family Studies)
- Interviews conducted virtually via phone or Zoom

Patient feedback on content and different versions of item wording

What were you thinking about when I asked this question?
Can you give me some examples of what this means?
Which makes more sense to you?
CancerSupportSource™-Spanish

Items and Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>Item (Spanish)</th>
<th>Item (English)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Well-Being</td>
<td>Sentirse irritado</td>
<td>Feeling irritable</td>
</tr>
<tr>
<td></td>
<td>Sentimientos de tristeza o depresión‡</td>
<td>Feeling sad or depressed‡</td>
</tr>
<tr>
<td></td>
<td>Sentirse nervioso o con temor†</td>
<td>Feeling nervous or afraid†</td>
</tr>
<tr>
<td></td>
<td>El futuro y lo que se espera†</td>
<td>Worrying about the future and what lies ahead†</td>
</tr>
<tr>
<td></td>
<td>Sentirse solo o aislado‡</td>
<td>Feeling lonely or isolated‡</td>
</tr>
<tr>
<td></td>
<td>El seguro médico o las preocupaciones por el dinero</td>
<td>Health insurance or money worries</td>
</tr>
<tr>
<td></td>
<td>La familia, los niños o los amigos</td>
<td>Worrying about family, children and/or friends</td>
</tr>
<tr>
<td></td>
<td>Encontrarle un propósito y sentido a la vida</td>
<td>Finding meaning and purpose in life</td>
</tr>
<tr>
<td>Symptom Burden &amp; Impact</td>
<td>Desplazarse o moverse (caminar, subir escaleras, levantarse, etc.)</td>
<td>Moving around (walking, climbing stairs, lifting, etc.)</td>
</tr>
<tr>
<td></td>
<td>Problemas para dormir</td>
<td>Sleep problems</td>
</tr>
<tr>
<td></td>
<td>Cambios o alteraciones en el trabajo, la escuela o la vida en el hogar</td>
<td>Changes or disruptions in work, school or home life</td>
</tr>
<tr>
<td></td>
<td>El transporte para llegar a su tratamiento y sus citas</td>
<td>Transportation to treatment and appointments</td>
</tr>
<tr>
<td></td>
<td>Dolor o molestias físicas</td>
<td>Pain and/or physical discomfort</td>
</tr>
<tr>
<td></td>
<td>Sentirse demasiado cansado para hacer las cosas que necesita o quiere hacer</td>
<td>Feeling too tired to do the things you need or want to do</td>
</tr>
<tr>
<td></td>
<td>Manejo los efectos secundarios del tratamiento (náuseas, tinchaón, etc.)</td>
<td>Managing side effects of treatment (nausea, swelling, etc.)</td>
</tr>
<tr>
<td></td>
<td>Pensar con claridad (p. ej., problemas de concentración, memoria, o fatiga mental)</td>
<td>Thinking clearly (e.g., “chemo brain,” ”brain fog”)</td>
</tr>
<tr>
<td>Body Image &amp; Healthy Lifestyle</td>
<td>Alimentación y nutrición</td>
<td>Eating and nutrition</td>
</tr>
<tr>
<td></td>
<td>Su imagen física y sus sentimientos respecto a la manera cómo se ve</td>
<td>Body image and feelings about how you look</td>
</tr>
<tr>
<td></td>
<td>Cambio de peso reciente (aumento o pérdida de peso)</td>
<td>Recent weight change (gain or loss)</td>
</tr>
<tr>
<td></td>
<td>Hacer ejercicio y estar físicamente activo</td>
<td>Exercising and being physically active</td>
</tr>
<tr>
<td>Health Care Team Communication</td>
<td>La comunicación con su médico</td>
<td>Communicating with your doctor</td>
</tr>
<tr>
<td></td>
<td>Toma de decisiones acerca del tratamiento</td>
<td>Making a treatment decision</td>
</tr>
<tr>
<td>Relationships &amp; Intimacy</td>
<td>Intimidad, función sexual o fertilidad</td>
<td>Intimacy, sexual function and/or fertility</td>
</tr>
<tr>
<td></td>
<td>Problemas en su relación con su esposa(o)/ pareja</td>
<td>Problems in your relationship with your spouse/partner</td>
</tr>
<tr>
<td>Tobacco, Alcohol, or Substance Use</td>
<td>Consumo de tabaco o drogas (por su parte o de alguien en su hogar)</td>
<td>Tobacco, alcohol, or other substance use</td>
</tr>
</tbody>
</table>

Note: † = 2-item depression risk; ‡ = 2-item anxiety risk

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Emotional Well-Being

Anxiety
- Worrying about the future and what lies ahead
- Feeling nervous or afraid

At risk for clinical anxiety

Depression
- Feeling sad or depressed
- Feeling lonely or isolated

At risk for clinical depression

- Untreated depression and anxiety can have serious consequences
- Embedded within CSS-Spanish are subscales to flag people at-risk for clinical levels of depression and anxiety
- Staff are notified when a flag is activated and can provide appropriate follow-up
III. Screener Validation
210 participants completed CSS-Spanish and comparison measures in an online survey conducted 11/2021 – 8/2022

Recruitment occurred via:
- CSC National Platforms
- Cancer Experience Registry
- MyLifeLine online community
- CSC & GC Network partners
- Advocacy partners
- Nueva Vida
- SHARE
- National survey polling firm

Participants identified as more than a dozen Hispanic and Latino origins, with the largest groups including Mexican (40%), Columbian (8%), Puerto Rican (8%), Cuban (7%), and Dominican (7%)
Internal reliability:
High internal consistency ($\alpha=.95$) and test-retest reliability ($r=.92$); individual factor ICCs $\geq .79$

Confirmatory Factor Analysis:
Good to acceptable model fit: $\text{RMSEA}=0.08[\text{CI } = 0.069-0.086]$, $\text{SRMR}=0.06$, $\text{CFI}=0.90$, $\text{TLI}=0.89$, $\chi^2=546.48$

Scale correlations with comparison validation measures:
Strong and statistically significant correlations (absolute value of $r >0.50$; $p<.05$) observed between total CSS-Spanish distress and all seven domains of PROMIS29 (depression, anxiety, social function, physical function, sleep disturbance, fatigue, pain interference), as well as PHQ-2, GAD-2, and NCCN Distress Thermometer

Known groups validity:
Greater total distress associated with cancer recurrence ($r=.24$, $p<.001$), time since diagnosis ($r=-.17$, $p<.001$), metastatic status ($t=4.150$, $p<.001$), and active treatment ($t=3.151$, $p<.001$)

CancerSupportSource-Spanish Statistical Validation Results
Today, how CONCERNED are you about...

0 = Not at all concerned
1 = Somewhat concerned
2 = Moderately concerned
3 = Seriously concerned
4 = Very seriously concerned

- Emotional well-being
- Symptom burden and impact
- Body image and healthy lifestyle
- Healthcare team communication
- Relationships and intimacy
- Tobacco, alcohol, and substance use

n = 210
In our sample (N=210), 71% of respondents reported depression or anxiety at levels triggering a clinical “risk flag.” In the full program, staff receive an automatic notification so that persons at risk can receive needed follow-up.
IV. Program Implementation
How It Works
CancerSupportSource-Spanish Distress Screening and Referral

Respondent Completes Screener

- Respondent Receives Customized Resource Report
- Staff Receives Automated Report
- Automated At-Risk Flags
- Referral and Follow-Up

★ Development and psychometric testing for this screener described in previous slides
How It Works
Respondent Completes Screener & Chooses Desired Support

Respondent Completes Screener

How, ¿cuán PREOCUPADO está sobre… Sentimientos de tristeza o depresión

- Nada
- Levemente
- Moderadamente
- Seriamente
- Muy serio

Sentimientos de tristeza o depresión: Díganos cómo podemos brindarle ayuda
- Hablando con un miembro del personal
- Proporcionándole recursos escritos o en línea
- No es necesario tomar ninguna acción
How It Works
Customized and Automated Reports

Respondent Customized Resource Report

Automated Staff Report

Automated At-Risk Flags
How It Works
Staff Facilitate Referrals and Follow-Up

Review Referrals

Making a treatment decision
Status: In progress

Patient: peyton SAMPLE
Form name: 
Doctor: 
MRN: 01/01/1990
Birthday: 
Support assigned: Test MYCARE
Referral date: 12/13/2022
Email: peytonypmail@yopmail.com
Mobile phone: 

Status History

<table>
<thead>
<tr>
<th>Date/Time</th>
<th>Reminder Date</th>
<th>Notes</th>
<th>User</th>
</tr>
</thead>
<tbody>
<tr>
<td>12/13/2022</td>
<td>14:13 PM</td>
<td>Add detailed case notes here.</td>
<td>Peyton LENGAUCHER</td>
</tr>
<tr>
<td>12/13/2022</td>
<td>14:12 PM</td>
<td>Assigned by Peyton LENGAUCHER</td>
<td>Test MYCARE</td>
</tr>
</tbody>
</table>

Automated Report Tracks Referrals History and Status

Referral and Follow-Up

My Support Care Plan

Referrals History

<table>
<thead>
<tr>
<th>Date</th>
<th>Referral</th>
<th>Assigned To</th>
<th>Status</th>
<th>History</th>
</tr>
</thead>
<tbody>
<tr>
<td>12/13/22</td>
<td>Sleep problems</td>
<td>Test MYCARE</td>
<td>Resolved</td>
<td>- Assigned by Peyton LENGAUCHER - Add detailed case notes here - Referral closed by Peyton LENGAUCHER</td>
</tr>
<tr>
<td>12/13/22</td>
<td>Making a treatment decision</td>
<td>Test MYCARE</td>
<td>In progress</td>
<td>- Assigned by Peyton LENGAUCHER - Add detailed case notes here</td>
</tr>
<tr>
<td>12/13/22</td>
<td>Worrying about family, children and friends</td>
<td>Test MYCARE</td>
<td>In progress</td>
<td>- Assigned by Peyton LENGAUCHER - Add detailed case notes here</td>
</tr>
<tr>
<td>12/13/22</td>
<td>Risk for depression</td>
<td>Test MYCARE</td>
<td>In progress</td>
<td>- Assigned by Peyton LENGAUCHER - Add detailed case notes here</td>
</tr>
</tbody>
</table>
V. Summary
CSS-Spanish is a **psychometrically robust measure of psychosocial distress** among Hispanic and Latino individuals with cancer.

CSS-Spanish was created using **gold-standard methods** for translation and an **iterative process** of testing that included feedback from Spanish-speaking Hispanic and Latino individuals living with cancer and a project advisory board.

In full program implementation, it can facilitate distress screening, referral, and follow-up to rapidly assess unmet needs and enhance well-being.

Benefits of CSS-Spanish can be optimized when implemented with a strong case management system and access to Spanish-language community resources.
Thank you
efortune@cancersupportcommunity.org