Cultural and Linguistic Adaptation of a Colorectal Cancer Screening Decision Aid for Latinos with Limited English Proficiency

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Rationale

- The US has become linguistically and culturally diverse.
- US population grow; 2010-2050 projections
  - Non-Hispanic Whites: 64.7% - 46.3%
  - Hispanics: 16.0% - 30.2%
  - AA: 12.9% - 13%
  - Asian Americans: 4.6%-7.8%
- Languages spoken at home:
  - English: 215 million
  - Spanish: 28 million
  - Chinese: 2 million
  - Followed by French, German, and Italian
Hispanics ~50.5 million, and roughly 3/4 of Hispanics speak Spanish at home.

Many health communication interventions are first developed, tested, and refined in English speaking populations.

Researchers faced with the need to adapt existing interventions from English into Spanish.
Colorectal cancer (CRC) is the second most common cancer among Latino men and women.
- Second-leading cause of cancer death for men
- Third-leading cause of death in women.

Hispanics have the lowest CRC screening rates of any major racial/ethnic group in the US.

Patient-physician communication barriers contribute to CRC screening disparities in limited English proficient (LEP) Hispanics.

Patient decision aids can overcome communication barriers and improve CRC screening test.
A pilot study to

1) To develop a linguistic and cultural adaptation of a multi-media English language decision aid for Spanish speaking Latinos.

2) To test the impact of the decision aid on patients intention to talk to their doctor regarding CRC screening and intention to obtain a CRC screening test.
Ko, Reuland, & Pignone, Cultural and Linguistic Adaptation Framework (CLAF), 2011, manuscript under review
Step 1: Appraise Original Intervention
Original Intervention

- Review the original intervention
- Identify and retain core elements: approach, rationale, structure, format, concepts, and theoretical underpinnings.
- “Don’t throw the baby out with the bathwater.”
- Show the original intervention (14 min. in length)
  http://decisionsupport.unc.edu/CHOICE6/Choice.html
Elements Retained

1. Basic factual content and overview of CRC
2. Presentation of CRC screening options
3. Comparative information regarding key attributes (efficacy, cost, time, frequency, discomfort, and risk)
4. Use of vignettes of actual patients and providers
5. Literacy levels
   - All text read aloud by a narrator
   - Patient and provider vignettes
   - Graphics
   - Animations
6. Theoretical underpinning: Prochaska’s Stages of Change Theory: pre-contemplation, contemplation, or preparation
Step 2: Review Relevant Literature
Relevant Literature

- Cultural values and systems affect CRC screening.
  - Hispanics tend to exhibit higher levels of interdependence, conformity, and collectivism.
  - Strong attachment, loyalty, and reciprocity toward members of their extended family (familism and relationship interdependence)
  - Tendency to build agreements, avoid conflict in interpersonal situations, and value the person-to-person interaction (personalism).
Step 3: Assess Regional Context and Engage Stakeholders
Assessing Context

- Review the state and regional demographic trends
  - NC experienced relatively recent but very rapid growth in Latino population
- Latino population increased by 111% between 2000-2010.
  - Mexican origin (66%)
  - El Salvador, Guatemala, Honduras, and others.
- More likely to live in poverty and less likely to have health insurance than non-Latinos.
- Newly emerging communities-lacks social networks and institutions that facilitate immigration adaptation to the US and support economic development among Latinos.
Assessing Regional Context Cont’d

- Regional CRC rates and screening patterns.
- 4th most commonly diagnosed cancer

Colorectal Cancer Screening Rates in North Carolina
*Data from the North Carolina State Center for Health Services
Engage Stakeholders

- By engaging stakeholders (gastroenterologists, promotoras (lay health promoters), clinic leaders, and staff at clinics, serving a large Latino population.
  - Understand the context
  - Gives us a platform for collaboration
  - Interview and focus group findings guided the development of the moderator guide for the target population.
Step 4: Engage the Target Population
Recruitment

- Two health centers
- Identified eligible patients through clinic patient records and appointment logs
- Sent invitation letters to participants
- Eligibility (age 50-75, self-identified as Hispanic/Latino, had appointment within the last two years, no high risk for CRC)
Focus Groups

- 4 Focus groups (2 with women and 2 with men)
- Six key topics:
  - Latinos’ views of CRC explanatory models
  - Latinos’ attitudes toward CRC screening
  - Barriers and facilitators of CRC screening
  - Patient’s experience with doctor-patient communication around CRC screening
  - Suggestions on how to adapt a current English version of a CRC decision aid to Spanish speaking audience.
  - Preferred content and format of the current video intervention.
Data Analysis

- The process involved 3 stages (Miles & Huberman, 1994).
- First stage: developed notes on key themes, provided feedback to the moderator, discussed and relate themes to scripts.
- Second stage: generated tentative labels to capture the essence of each idea and compared and contrasted our notes.
- Third stage: reviewed the data and clustered similar ideas together into themes and codes, created domain charts that mapped concepts and the interrelationship between concepts freehand.
## Demographic Characteristics of the Focus Group Participants

<table>
<thead>
<tr>
<th></th>
<th>(N=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>56 (± 4.5)</td>
</tr>
<tr>
<td><strong>Country of origin</strong></td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>13 (43)</td>
</tr>
<tr>
<td>Central America</td>
<td>8 (26)</td>
</tr>
<tr>
<td>Caribbean</td>
<td>5 (17)</td>
</tr>
<tr>
<td>South America</td>
<td>4 (13)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>16 (53)</td>
</tr>
<tr>
<td><strong>Speaks English</strong></td>
<td></td>
</tr>
<tr>
<td>Not at all/Not well</td>
<td>21 (70)</td>
</tr>
<tr>
<td>Well</td>
<td>9 (30)</td>
</tr>
<tr>
<td><strong>Years in the US</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;11</td>
<td>7 (23)</td>
</tr>
<tr>
<td>11-20</td>
<td>12 (40)</td>
</tr>
<tr>
<td>&gt;20</td>
<td>11 (37)</td>
</tr>
<tr>
<td><strong>Insurance</strong></td>
<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>20 (67)</td>
</tr>
<tr>
<td>Private</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Public (Medicare or Medicaid)</td>
<td>5 (16)</td>
</tr>
<tr>
<td>Other/unsure</td>
<td>2 (7)</td>
</tr>
</tbody>
</table>

| **Education**                |                 |
| 1 - 8 years                  | 13 (43)         |
| 9-12 years                   | 7 (23)          |
| 13+ years                    | 10 (33)         |

| **Employment**               |                 |
| Working full/part time       | 13 (40)         |

| **Household Income**         |                 |
| ≤ $20,000                    | 22 (73)         |
| >$20,000                     | 3 (10)          |
| Unsure/Declined to answer    | 5 (17)          |

| **Overall Health**           |                 |
| Excellent/very good/good    | 16 (53)         |
| Fair/poor                   | 14 (47)         |

| **Up to date with CRC screening** |     |
| Yes                             | 14 (47) |
| No                              | 16 (53) |

| **Comfort using a computer**  |     |
| Very comfortable/comfortable  | 10 (38) |
| Uncomfortable/Don’t know      | 14 (51) |

Data are M (±SD) or n (%) unless otherwise indicated.
Personalismo (Personalism)

- Participants wanted to see and meet one person in the decision aid who can be seen as a trusted guide.
- Personalismo is the tendency to value the person-to-person contact.

“I think you could reach people best if there were only one person who leads the whole video, who talks [and]…explains step by step and makes it more real, and more scientific…so that some of the medical opinions appear to support what he is saying.” [Man]
Familismo (Familism) and Relational Interdependence

- Participants told us to portray family members talking about CRC screening.
- Familismo is a belief that places a high value on the central position that the family holds in the life of the individual.

“...What would my family do if I had died? And that’s why I did it, out of love for my family. So look at my kids, look at my wife, the grandchildren that we have. And I did this for them, to prevent [cancer] and to last a little longer.” [Man]

“I think [the patients can be] accompanied by family because in real life, you don’t live isolated, especially not Hispanics. We live in families...It would be better with family members.” [Woman]
Miedo/Verguenza
(Fear/Embarrassment)

- Participants reported fear and embarrassment as barriers to talking to their doctors.
  - Fear of interacting with non-Spanish speaking doctors (power distance), embarrassed of not speaking English, to expose their naked bodies and private body parts.

“The majority of Latinos are afraid to talk with the medical doctors …. [if] one doesn’t know how to speak English…. Other reasons are that they are afraid that the medical doctor will be looking at their body, and that is why they are afraid.” [Woman]
Male participants linked a colonoscopy as a procedure that can diminish a man’s masculinity as they associated with homosexuality.

Machismo is the social construction of attitudes and traits recognized by members of a community as characteristics of men (Ramirez, 1999).

“[Women are] more submissive, but not men. And because of this and where he comes from, his machismo, and this and that and not wanting to get confused as a third gender [euphemism for homosexual]…that is why it’s important to emphasize to those men of strong character” [A man discussing about the colonoscopy procedure]
Confianza (Trust/Confidence/Assurance)

- Confianza can be translated into the English language as trust, confidence, or assurance.
- Participants told us to show Latino patients and providers.
- Show importance of building a trusting relationship with doctors

“Whether they’re professionals or patients…[the people] should be chosen of the Latino race…the video is directed at the Latino sector and people are going to feel more confianza (trust) if there’s a Hispanic doctor, a Hispanic professional talking in their own language…with their own gestures and all of that. Our people are going to feel more attracted, more interested…so that they pay attention to the problem.” [A man]
Many Latino patients reported incertidumbre (uncertainty) during the discussion of cost as there was no simple answer to the cost of having a FOBT or colonoscopy.

“Yes, I think that if you’re going to produce this [decision aid]…it’s important to talk about the costs…I think one should know, how much the bill will be for each polyp, right?” [A male focus group participant]
Step 5: Integration and Refinement
Integration of the Four Prior Steps

- **Script**
  - Default script - Direct translation of the English decision aid
  - Contextual background information
  - Capitalize on theoretical frameworks successfully applied for Latinos (TTM)
  - Perspectives of key stakeholders and the focus group participants

- **Production**
  - We hired actors and video production company
<table>
<thead>
<tr>
<th>Explicit Suggestions by Participants</th>
<th>Thematic Category from the Literature</th>
<th>Changes Operationalized by Researchers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Desire to meet a narrator</td>
<td>Personalismo (Personalism)</td>
<td>A narrator who viewers see (“meet”) and who guides them throughout the video.</td>
</tr>
<tr>
<td>2. Show families</td>
<td>Familistmo (Familism) Relational Interdependence</td>
<td>Pictures and a vignette of a couple talking about their experience with CRC screening • A video showing a female patient and her daughter talking to a non-Latino doctor</td>
</tr>
<tr>
<td>3. Language barriers</td>
<td>Miedo/Verguenza (Fear/Embarrassment)</td>
<td>Videos of bilingual doctors and health professionals explaining about CRC and CRC screening</td>
</tr>
<tr>
<td>4. Afraid to talk to the doctor</td>
<td>Miedo/Respeto (Fear/Respect) Power distance</td>
<td>Videos sequence modeling screening discussion with doctor • Patient vignettes encouraging patients to discuss with doctor</td>
</tr>
<tr>
<td>5. Screening is embarrassing. Show women talking reassuringly about screening</td>
<td>Verguenza (Embarrassment)</td>
<td>A video showing a female patient and her daughter talking to a non-Latino doctor</td>
</tr>
<tr>
<td>6. Address machismo directly</td>
<td>Machismo (Manhood)</td>
<td>A patient vignette where a Latino man tells other men to set aside feelings of machismo and re-evaluate their values</td>
</tr>
<tr>
<td>7. Show bilingual authoritative figures who are experts</td>
<td>Confianza (Trust/Confidence/ Assurance)</td>
<td>Bilingual health experts throughout the video. • A narrator who acts as a guide throughout the video • A video showing a female patient and her daughter talking to a non-Latino doctor</td>
</tr>
<tr>
<td>8. Discuss cost and acknowledge uncertainty</td>
<td>Incertidumbre acerca del costo (Cost Uncertainty)</td>
<td>A table comparing cost of FOBT and colonoscopy</td>
</tr>
</tbody>
</table>
Elements

- A narrator
- Male and female Hispanic actors
- Three bilingual health experts
- Video animation
- Screen shots
- Table of comparison (FOBT vs. Colonoscopy)
- Five segments: (1) Introduction, (2) FOBT, (3) Colonoscopy, (4) Talk to your doctor, and (5) Color brochures-readiness to be screened
Refinement

- n=18 cognitive interviews (verbal probing & think aloud)
  - Test the comprehension and acceptability of the message (verbal probing)
  - Usability of the decision aid (think aloud)

Nearly all (n=17, 95%) of the participants declined to use the mouse to navigate the DA because of unfamiliarity or discomfort using computers.

Participants suggested minor interface improvements such as bigger screen size and diagrams.
Multi-media Spanish Decision Aid

- Show a small segment of the decision aid (12 mins. in length)
  http://spanish-choice.org/main.html

Spanish for “CHOICE”
Offering Information about Cancer Prevention using New and Emerging System
Conclusion

- Health communication interventions need to be adapted linguistically and culturally for different racial/ethnic groups.
- We used a colorectal cancer screening decision aid as a case study to illustrate the adaptation process.
- We proposed the cultural and adaptation model with 4 steps and 1 integration and refinement step.
- Perhaps, this model could provide a framework for health intervention adaptation for researchers working with culturally and linguistically challenged populations.
¡Gracias!