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Cultural and Linguistic Adaptation of a Multimedia Colorectal Cancer Screening Decision Aid for Spanish Speaking Latinos

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Abstract

As the United States becomes more linguistically and culturally diverse, there is a need for effective health communication interventions that target diverse and most vulnerable populations. Latinos also have the lowest colorectal (CRC) screening rates of any ethnic group in the U.S. To address such disparities, health communication interventionists are often faced with the challenge to adapt existing interventions from English into Spanish in a way that retains essential elements of the original intervention while also addressing the linguistic needs and cultural perspectives of the target population. We describe the conceptual framework, context, rationale, methods, and findings of a formative research process used in creating a Spanish language version of an evidenced-based (English language) multimedia CRC screening decision aid. Our multi-step process included identification of essential elements of the existing intervention, literature review, assessment of the regional context and engagement of key stakeholders, and solicitation of direct input from target population. We integrated these findings in the creation of the new adapted intervention. We describe how we used this process to identify and integrate socio-cultural themes such as personalism (personalismo), familism (familismo), fear (miedo), embarrassment (vergüenza), power distance (respeto), machismo, and trust (confianza) into the Spanish language decision aid.

Keywords

Decision aid; Adaptation; Latinos; Limited English proficiency; Colorectal cancer screening

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The United States Latino population has grown 43 percent from 2000–2010, more than half of the growth of the entire U.S. population in the past decade. Latinos now number 50.5 million, and roughly three quarters of Latinos speak English at home (Passel, 2011). With these demographic changes comes a need for effective health communication interventions that target diverse, often vulnerable limited English proficient (LEP) populations. Ideally, development of new health communication interventions is informed by initial research and testing that is conducted in diverse populations including English speakers and Spanish speakers from the beginning. In reality, many health communication interventions are first developed, tested, and refined in English speaking populations. As a result, health communication interventionists are now often faced with the need to adapt existing interventions from English into Spanish in a way that retains essential components of the original intervention while also incorporating the linguistic and cultural perspectives and nuances of the target population (Barrer & Castro, 2006; Martinez & Urbana, 2001). In recent years, experts have placed greater emphasis on “adaptation” as opposed to translation (Geisinger, 1994; Heiderson, 1994; Nicholson, 1995). Although there is a growing literature on adapting and validating scales and other measurements (Bravo, Canino, Rubio-Stipec, & Woodbury-Farina, 1991; Carlson, 2000), less has been written about adaptation of interventions, and what is published has been focused on print-based education materials (Berkley-Patton, Goggin, Liston, Bradley-Ewing, & Neville, 2009; Simmons, Cruz, Brandon, & Quinn, 2011; Solomon et al., 2005). Few, if any studies, have described the adaptation of a patient-directed multimedia intervention into Spanish. In this paper, we use the adaptation of a computer-based, colorectal cancer (CRC) screening decision aid as a case study to illustrate such a process.

The Adaptation Problem and Context

CRC is the second leading cause of cancer mortality in the US among Latinos (Passel, Cohn, & Lopez, 2011). Although screening reduces the risk of death for CRC, there are striking racial disparities in screening. Latinos have the lowest CRC screening rate of any racial/ethnic group and are more likely than non-Latinos to present with late stage disease (Carcaise-Edinboro, & Bradley, 2008; Lafata, Divine, Moon, & Williams, 2006; Wolf, Baker, & Makoul, 2007). Latino populations tend to have less knowledge about CRC screening, and poor CRC-related communication with their doctors (Kim et al., 2005; Pignone, Harris, & Kinsinger, 2000). Communicating about CRC screening with a healthcare provider is a major factor that predicts screening, (Carcaise-Edinboro & Bradley, 2008; Holden, Jonas, Porterfield, Reuland, & Harris, 2010; Lafata et al., 2006; Wolf et al., 2007) and thus, improving communication can improve screening rates.

Patient decision aids are interventions designed to inform patients about health care decisions and help them overcome barriers related to health care communication and decision-making. An English language CRC screening decision aid, called CHOICE, has been rigorously developed, tested, and refined. It has been found to be effective in increasing patients’ intent to discuss CRC screening with their doctor, obtaining CRC screening, test ordering, and test completion (Kim et al., 2005; Miller et al., 2011; Pignone et al., 2000). We undertook the rigorous task of developing a cultural and linguistic

adaptation of this decision aid for Spanish speaking Latino patients living in North Carolina (NC).

Methods

Conceptual Framework for Adaptation

Figure 1 shows the cultural and linguistic adaptation framework (CLAF) that we have developed guided on the existing literature on intervention adaptation including hybrid model of adaptation (Martinez & Urbana, 2001), transcreation of education materials (Simmons et al., 2011), cultural sensitivity approach to existing interventions (Dutta, 2007), and cultural adaptation of evidence-based treatments (Lau, 2006). We conceptualized the adaptation process as one of locating an optimal point along a spectrum between complete *de novo development* of an intervention at one extreme, and *direct or literal translation* of the existing English decision aid (or *dubbing* of the video) at the other end of the spectrum (Figure 1). Our intent was neither to abandon useful and applicable knowledge gained from development and testing of original English language versions nor to merely translate an existing decision aid. The CLAF depicts the adaptation process as consisting of the following four key formative data collection steps followed by an integration and refinement step:

Step 1) Appraise existing intervention—We reviewed the original decision aid intervention and associated published data with its developers in order to identify core elements of the intervention’s approach, rationale, structure, format, concepts, and theoretical underpinnings. We identified and chose to retain the following elements: 1) the basic factual content and overview of CRC, though we added Latino-specific screening data (regarding the disparity), 2) the presentation of cancer screening options including FOBT and colonoscopy as the two widely available CRC screening options, 3) comparative information regarding the key attributes of these two screening tests (efficacy, cost, time required, test frequency, discomfort, and risk of complications), 4) the use of vignettes from actual patients and providers, 5) the emphasis on and techniques for keeping the information accessible across literacy levels (i.e. having all written text read aloud by a narrator, and technical terms and concepts explained using easy-to-understand narration, vignettes, graphics, and animations) (see Figure 2), and 6) the design elements connected to the decision aid’s central theoretical underpinning, Prochaska’s Stage of Change Theory (Prochaska, Redding, & Evers, 2002). This included having decision aid viewers indicate their readiness for screening (pre-contemplation, contemplation, or planning for action) by selecting a stage-targeted, color-coded brochure.

Step 2) Review relevant literature—We reviewed the growing literature on patient-level, provider level, and structural barriers to CRC screening. A summary of this review is beyond the scope of this paper. However, within the health behavior literature we found descriptions of distinct cultural values and systems that may affect health behaviors such as CRC screening and that could affect the perceived relevance and acceptability of the decision aid. For example, compared with members of the dominant “Anglo” US culture, Latinos tend to exhibit higher levels of interdependence, conformity, and collectivism. Other

culturally linked characteristics include a tendency to build agreement and avoid conflict in interpersonal situations, to value the person-to-person interaction (personalism) and to show strong attachment, loyalty, and reciprocity toward members of their extended family (familism) (Marin, Sabogal, Marin, Otero-Sabogal, & Perez-Stable, 1987).

Step 3) Assess regional context and engage stakeholders—We reviewed state and regional demographic trends and determined regional screening patterns. We also convened both group meetings and individual meetings with regional stakeholders. Stakeholders included researchers with expertise in CRC screening, gastroenterologists, *promotoras* (i.e., lay health promoters), clinic leaders and staff at regional community health centers (CHCs) that serve Latino populations in central NC to understand and incorporate their perspectives about CRC screening in the target population.

These efforts confirmed that, like other southeastern states, NC experienced relatively recent but very rapid growth in Latino populations (Pew Hispanic Center, 2011). The state's Latino population increased by 111% between 2000 and 2010 and continues to grow rapidly. The majority of NC's Latino population (58%) is foreign born, and 82% speak Spanish at home (Pew Hispanic Center, 2011). Most are of Mexican origin (66%), though 24% come from El Salvador, Guatemala, Honduras, Nicaragua, Colombia, Peru, Ecuador, Puerto Rico, Cuba, and the Dominican Republic. NC Latinos are more likely to live in poverty (27%) and less likely to have health insurance than non-Latinos (Silberman et al., 2003). The migration and acculturation experience of Latinos living in NC are characteristic of newly emerging Latino communities, that is, communities with historically low numbers of Latino residents (Williams, Alvarez, & Andrade Hauck, 2002). Because newly emerging Latino communities typically lack the social networks and institutions that facilitate immigrant adaptation to the U.S. and support economic development among Latinos, the experiences of Latinos settling in them may differ from their peers in more established Latino communities (e.g., Los Angeles) (Williams et al., 2002). Over one hundred CHCs in NC serve large Latino populations from both urban and rural areas, and these centers typically do not have organized systems for CRC screening in place. The information gathered from the meetings and interviews influenced the development of the moderator guide for the Latino patient focus groups.

Step 4) Solicit input from target population in adaptation—We used formal focus group methods for this step (methods/findings below). Our aims were a) to confirm and expand upon key findings in the literature, emphasizing socio-cultural influences on CRC screening and b) to engage the target population directly in the process of adapting the decision aid for a Spanish speaking audience.

Step 5) Integrate findings and refine the decision aid—In developing the initial script and storyboard for the prototype Spanish language decision aid, we began with a direct translation of the English version into Spanish. This step was conducted by researchers and staff who were native Spanish speakers. We then modified each scene or segment based on suggestions and themes from our focus groups and/or on findings from other process steps to generate the new storyboard. Our CLAF (Figure 1) depicts this

adaptation process as cyclical since we applied the integration process iteratively for different segments in the decision aid.

We then employed a video producer who was experienced in filming health-related topics. Because of the importance our focus group participants placed on having a charismatic and personable narrator (see *personalismo* in results), we hired a professional actor who was Mexican to narrate. Other actors were volunteers and included members of stakeholder groups (bilingual clinicians and a *promotora*) and some of the focus group participants. Actors rehearsed the script and discussed their performance with the investigators and director of the video production company before filming. The resulting prototype was 14 minutes in length and produced as a video. Figure 2 shows screen shots from the prototype Spanish language decision aid (see also Appendix for segments of the decision aid). And, finally we refined the decision aid using usability testing and cognitive interviews.

Patient Focus Group

Recruitment—We conducted four focus groups: two male groups and two female groups (6–10 per focus group, n=30). Eligibility criteria included self-identification as Hispanic/Latino, self-report of speaking Spanish less than “very well,” age 50–75 years old, and absence of personal or family history of CRC, colon polyps, or inflammatory bowel disease. Sessions were held at the health centers from which patients were recruited, a community health center and an academic internal medicine practice in central NC. We sent recruiting letters to 214 potential patient participants at the health centers; 14 letters were returned due to insufficient address. Of 200 letters, 49 (25%) participants responded to the letters, and of those, 33 (67%) were eligible and agreed to participate. Three participants did not show up to the focus group leaving a total of n=30.

Data collection—Focus group sessions lasted 1.5 to 2 hours and were conducted in Spanish. One member of the research team fluent in Spanish moderated the groups. After soliciting their general attitudes, experiences, and perspectives on CRC screening, the moderator showed segments of the decision aid, pausing between sections to fully translate and explain (conceptually) the content to the participants. For each segment, the moderator solicited participant feedback and input about how the content, format, graphics, and individuals portrayed in the video could be adapted to increase relevance and message effectiveness. Focus groups were audio recorded, transcribed verbatim, checked for accuracy, and translated from Spanish into English. All members of the investigative team were bilingual and both the original Spanish transcripts and translated versions were reviewed and referred to during post-focus group debriefing sessions.

Data analysis—The focus group analysis was conducted in three stages (Miles & Huberman, 1994). First, researchers met after each focus group, developed notes on key themes, and provided feedback to the moderator for the next focus group to clarify emerging themes and discuss how themes and suggestions could be incorporated into the decision aid. Second, four members of the research team (all bilingual) independently reviewed each transcript to identify main ideas and meanings. We generated tentative labels to capture the essence of each idea and compared and contrasted our notes. Third, we reviewed the data

and clustered similar ideas together into themes and codes representative of each theme. We also created freehand domain charts that mapped the interrelationship between concepts. We evaluated atypical cases that did not fit patterns identified for the majority.

Results

Demographic Characteristics of the Focus Group Participants

The average age of the participants was 56 (± 4.5) (Table 1). The majority were either from Mexico (43%) or Central America (26%) generally reflecting the demographics of the NC Latino population. None of the participants reported speaking English “very well.” Most reported speaking English “not well” (50%) or “not at all” (20%). Most were uninsured (67%), had eight or fewer years of formal education (43%), were not working (60%), and had an annual household income of less than \$10,000 (60%). About half reported being up-to-date with CRC screening (47%). A large proportion reported (44%) not knowing how to use a computer, and few used one on daily basis (15%).

Focus Group Themes

We identified themes regarding barriers and facilitators to CRC screening, many of which were reflected in existing literature. Because we also explicitly solicited input from the target population on how to adapt the decision aid, we were not only able to map these themes to those found in the published literature, but also to operationalize changes in the decision aid. Table 2 summarizes some of the key adaptations to the decision aid suggested by participants, the general theme(s) that these suggestions corresponded to, and some of the specific changes we make to “operationalize” these in the decision aid.

Personalismo (Personalism)—Focus group participants suggested and agreed they would prefer to actually see and “meet” one person in the decision aid who could be seen as a trusted guide in the video, rather than hear an unseen “omniscient” narrator as in the original English video. The participants saw the guide as someone who explains or interprets the medical information from a credible lay person perspective. As one male participant said,

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]

This finding is consistent with other findings on *Personalismo* (Personalism), the tendency to value the person-to-person connection highly (Inclan, 1990). Some research suggests that intervention messages that were “personalized” to the Latino community were more successful to promote healthy behaviors (Elder et al., 2005).

Another participant saw this guide as someone who can persuade:

One general leader. It’s like selling stuff on TV...here is one individual who can... sell you shoes that walk by themselves. It’s the same principle, but applied scientifically... He’s a friendly, likeable person, who conveys interest but at the

same time explains the need [for screening] and endorses the doctors' intervention.
[Man]

Familismo (Familism) and Relational interdependence—Focus group participants also universally suggested the importance of portraying family members participating in decisions about CRC screening rather than seen individual patients in the original English video. *Familismo* refers to the tendency to place a high value on the central position that the family holds in the life of the individual (Ho, Rasheed, & Rasheed, 2004), and to view decisions by the individual in the context of the well-being of the family. One man spoke about the importance of keeping oneself healthy to be around family members longer,

...What would my family do if I had died? And that's why I [got screened], 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 be around a little longer.
[Man]

Similarly, upon seeing the English decision aid, a female participant suggested depicting family members communicating with a doctor about screening:

I think the patients should be accompanied by family [during medical encounters] 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 and Verguenza (Fear and Embarrassment)—Many participants brought up the topics of *miedo* (fear) and *verguenza* (embarrassment) together as barriers to talking to their doctors about CRC screening and to screening itself. Some reported fear of interacting with non-Spanish speaking medical doctors. For some, the fear of not speaking English had led them to delay their medical care or to take a passive position during medical encounters, failing to ask follow-up questions, and pursuing clarification of medical discussions with their providers. Sometimes, the words fear and embarrassment were used interchangeably when associated with language barriers. Participants reported feeling “afraid to talk to their doctors,” but also “embarrassed about their limited language skills” to communicate and relay information about their health. Some investigators have linked this barrier to communicating with a doctor to a related theme of *power distance*, or a tendency to show deference to authority figures, including the wealthy and those in prestigious professions (Dutta, 2007). Those who had a trusting relationship with a doctor who spoke Spanish reported overcoming these fears and embarrassments and feeling self-confidence in talking to their doctors (see also *confianza* below).

Male and female participants discussed embarrassment (*pena* or *verguenza*) with undergoing a colonoscopy exam because it involved examination of a private body part. Women also reported “embarrassment” exposing their naked bodies to the doctor's view and touch (Goldman, Diaz, & Kim, 2009).

Machismo—Machismo has been defined in the literature as the social construction of attitudes and traits recognized by members of a community as characteristics of men as strong or having an exaggerated sense of masculinity (Ramírez & Casper, 1999). The term

“machismo” was cited specifically by our male focus group participants as an influential factor in Latino men’s reluctance to undergo CRC examination. Several male participants linked a colonoscopy as a procedure that can diminish a man’s masculinity, at times associating it with homosexuality. We found similar reports regarding other procedures involving examination of the rectum (Fernandez et al., 2008; Goodman, Ogdie, Kanamori, Canar, & O’Malley, 2006). A male participant was candid about machismo and the potentially stigmatizing link between having a colonoscopy and homosexuality among some Latino men. He suggested that the Spanish language decision aid speak to these men directly:

[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 with strong character. [A man discussing the colonoscopy procedure]

Confianza (Trust/Confidence/Assurance)—*Confianza* was another theme that came up frequently in the focus groups. *Confianza*, depending on its use, can be translated into English as trust, confidence, or assurance. Participants talked about the importance of portraying Latino patients and providers in the decision aid to capture the language and the nuance in gestures associated with the Latino culture as a way to build trust. This finding is consistent with the literature on patient-providers’ race and language concordance suggesting the importance of shared identities between patients and providers, including ethnicity, race, and language (Flaskerud, 1990; Sawyer et al., 1995). Several participants said that the message would build trust if delivered by someone for whom Spanish was his/her first language and for whom the subtle non-verbal communication, like cultural gestures, would enhance their trust in and the appeal of the content of the decision aid (Cooper et al., 2003; Lee, Batal, Maselli, & Kutner, 2002).

Whether they’re professionals or patients... [the actors] 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. [Man]

Cost uncertainty—Cost and cost-uncertainty around CRC screening emerged as common themes. For many, the cost of CRC screening test was considered a crucial factor since the “majority of people [Latinos] are without medical insurance.” Some leaned toward the FOBT if both the FOBT and the colonoscopy were similarly effective in finding colon cancer:

“If [for] the more expensive one, I’m going to pay \$1000, [and this test] is as effective as the other one that’s \$20, I’ll go with the cheaper one” [A man]

Although a few said that since a positive test of FOBT (finding blood in the stool) would require follow-up testing with a colonoscopy, they would skip FOBT all together and go directly with a colonoscopy “to get rid of the doubt at one time.”

Cost uncertainty was as much of a concern as cost for some, as they recognized that there is no simple way to estimate a person's out-of-pocket cost of screening using either FOBT or colonoscopy. Participants recognized that each test could lead to a cascade of further testing that could add to participants' original costs. Participants suggested that acknowledging this cost uncertainty would allow people to be prepared to consider the range of factors that can influence cost with each procedure.

Yes, I think that if you're going to produce this [decision aid]...about the colon, it's important to talk about the costs, because people, you get scared when you read \$1000 or something...and what are you going to do in that moment? It's a lot...and if they find polyps, they get rid of them. But I think you should know, how much will the bill be for each polyp, right? [Man]

Discussion

In this paper, we present the multi-stage, formative research process and findings for the cultural and linguistic adaptation of a CRC decision aid for Spanish speaking Latino populations. Conceptually, the process involves integration of findings from four information gathering steps, which included appraisal of the existing intervention, review of the literature, assessment of the regional health care context and engagement of the regional stakeholders, and soliciting direct involvement of the target population in confirming and, ultimately, operationalizing the findings.

While other case studies have described adaptations of printed health educational materials (Berkley-Patton et al., 2009; Simmons et al., 2011; Solomon et al., 2005) to our knowledge, this is the first description of such an adaptation that involves a patient targeted multimedia decision aid intervention. Compared with printed materials, multimedia interventions offer new health communication tools and new opportunities and challenges for interpretation of cultural and linguistic nuance. Thus, we believe this study complements and extends previous methodologic studies on cultural and linguistic adaptation, and it will be useful to other intervention developers.

Our cultural and linguistic adaptation framework (CLAF) (Figure 1) is conceptually similar to the previously described hybrid model where the adapted intervention bridges the need for fidelity of the original intervention with the need for cultural relevance and specificity (Barrera & Castro, 2006; Castro, Barrera, & Martinez, 2004; Martinez & Urbana, 2001). The adaptation process was guided by empirical findings and relied on information gathered through the literature and data collection (Barrera & Castro, 2006; Lau, 2006). Barrera and Castro (2006) reported that information gathering is a main adaptation step, and investigators can resort to concurrent activities such as reviewing literature, conducting surveys, and qualitative research to inform the content of the needed adaptation. Other experts have referred to this general process as "transcreation" (Bender, Harbour, Thorp, & Morris, 2001; Quinn, Hauser, Bell-Ellison, Rodriguez, & Frias, 2006; Solomon et al., 2005) and cultural sensitivity approach (Dutta, 2007).

In our adaptation process, we sought to integrate and corroborate the information gathered through literature review with suggestions from stakeholders and focus groups with Latino

patients. Further, we reflected on the general themes (such as familism and embarrassment), barriers, and facilitators around CRC screening of the focus group participants and explicitly solicited ways to address these themes with specific changes in the Spanish-language decision aid. This process brought members of the target population close to the actual integration process, allowing them to help place the adaptation questions along the spectrum of de novo development to direct, literal translation.

Our focus group participants described Latino immigrants' tendency to value social relationships, and their desire to see these values reflected in interventions targeted to Latinos to enhance effectiveness. Two aspects of social relationships that were described by our participants were consistent with the literature on personalism and familism. Personalism and familism have been extensively reported and described in the literature as cultural concepts that reflect the values of Latino immigrants in the context of social network and relational interdependence. Our participants suggested incorporating changes in the Spanish language CRC decision aid that reflect values of personalism (Figure 2; Picture b) and familism (see example in Figure 2; picture a and d) to enhance relevance, increase trust, and maximize effectiveness among Latinos.

The importance of developing quality relationships goes beyond Latinos' interaction with family and friends to include healthcare providers. Unfortunately, the language barrier that Latino immigrants experience in the U.S. tends to hinder their interaction and the opportunity to develop a trusting relationship with their healthcare providers. Our focus group participants reported fear of interacting with their doctors and being embarrassed about their limited English language skills. These fears and embarrassments, however, tended to dissipate in the presence of an English interpreter. Having a trustable doctor was notably important to our participants. This may be particularly important within the context of CRC screening as CRC screening is a clinical procedure that often is initiated with a discussion with a healthcare provider (Kim et al., 2005; Pignone et al., 2000). To help build confidence interacting with doctors, the Spanish adaptation included a more explicit coaching and modeling presenting a video where a family is seen comfortably interacting with a doctor, unlike the English decision aid which did not address this issue (Figure 2, Picture d).

Our study also found gender-specific barriers to CRC screening among Latino men. Our participants reported that Latino men tended to associate colonoscopy procedure with homosexuality. This belief has been corroborated with findings from the literature on colonoscopy (Diaz, Roberts, Goldman, Weitzen, & Eaton, 2008; Goldman, Diaz, & Kim, 2009; Kim et al., 2005) as well as digital rectal exam (Goodman et al., 2006). We addressed this potential barrier in our Spanish decision aid by having a Latino man recruited from our focus groups address the issue directly. Speaking largely extemporaneously on camera, he encourages other men to consider the importance of making good health decisions against maintaining a *machista* image. Additionally, the Spanish decision aid included messages of familism and relational interdependence to emphasize that the needs to stay healthy for their family supersedes their individual beliefs.

Cost and cost uncertainty were themes that also emerged from the focus group discussion and interviews with stakeholders. Cost has been extensively described in the literature both qualitatively and quantitatively as a barrier to obtaining a CRC screening test in all race/ethnic groups (Goodman et al., 2006; Klabunde et al., 2005), particularly among Latinos as many are in a more socio-economically disadvantaged situation than other race/ethnic groups in the U.S. Cost uncertainty, on the other hand, was unexpected and enlightening yet a justified concern of our participants since both FOBT and colonoscopy can lead to further testing that would increase an individual's out-of-pocket cost. Addressing cost uncertainty was very challenging to present in the decision aid because our goal was to create a decision aid that was short, brief, and less than 15 minutes in length. Nonetheless, we took opportunities to address this concern by providing information on the range of costs of FOBT and colonoscopy independently, and embedded messages that cost can increase when results of FOBT or colonoscopy are positive and can also decrease with insurance plans as they often cover CRC screening, as well as applying for financial assistance for those without insurance.

Strengths and Limitations

A strength of this study is that it provides a model for integration of information and data from a variety of sources to optimize an adaptation of a multi-media intervention. Rather than focusing our Spanish adaptation solely on the focus group findings, we corroborated the focus group findings with the literature on CRC screening among Latinos as well as interviews with key stakeholders to identify broad cultural concepts and to operationalize them within the specific context of communication and decision making about CRC screening. We also found unique perspectives and values that were not captured in the literature review. Additionally, we specifically present a conceptual framework (CLAF) of the formative research process that few if any studies have described—a framework for developing an adaptation of an existing multi-media health communication intervention from one language and culture into another. We believe other intervention developers will find this framework useful and generally applicable when faced with the need to adapt a previously developed and tested intervention, regardless of the target population characteristics, specific intervention content, or delivery context.

Our study also has limitations that provide fertile ground for additional research to better understand how to promote optimal health communication to improve health behavior in diverse populations. First, our focus groups focused on patient population, and we cannot generalize our findings to a non-patient population. However, we validated our focus group findings with the literature on Latinos regarding CRC and CRC screening and were able to identify universal concepts affecting Latino populations. Second, our participants are from newly emerging Latino communities, and the majority of the participants were of Mexican origin and from low-income families. The CRC related experiences of Latino immigrants from more established Latino communities, who have immigrated to the US for educational reasons, and/or who are from high-income families may differ from the experiences of the participants we interviewed.

Conclusion

To reduce health disparities, it is critical to develop new interventions that address the needs of diverse US populations. In addition to developing and testing new interventions in diverse populations, it is also important to identify ways to adapt previously developed and tested English-language health communication interventions that can facilitate communication and decision making in diverse populations. In this case study of a multi-step adaptation of a CRC decision aid, we identify the essential elements of the original intervention as well as the language needs and socio-cultural context of CRC screening among Latino immigrants through extensive review of the literature, interviews with key stakeholders, and direct interaction with the Latinos through focus groups. Future studies may want to corroborate explicit suggestions from the focus group participants with the literature on CRC and interviews with key stakeholders to help uncover cultural values that can be operationalized into specific changes in the Spanish-language intervention.

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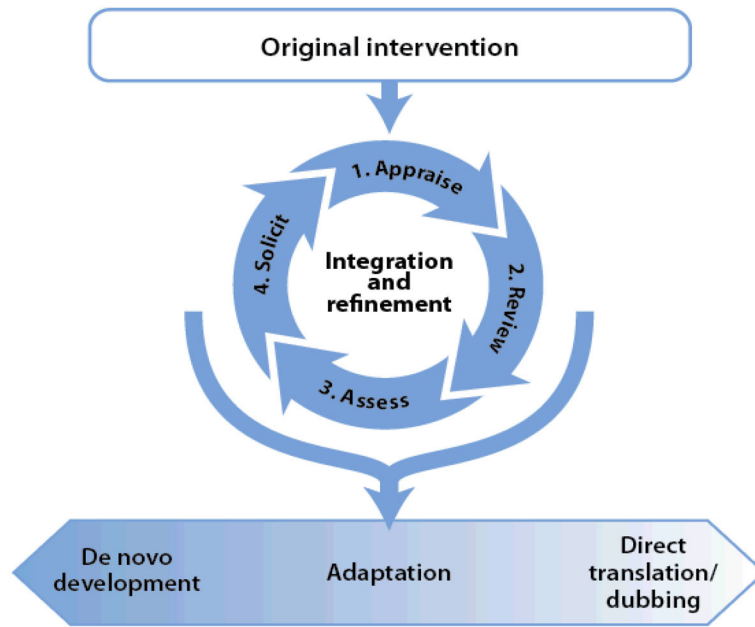


Figure 1. Cultural and linguistic adaptation framework (CLAF) for existing decision aid intervention.



Figure 2. Screen shots from the prototype Spanish language decision aid: a) Initial screen, b) Narrator, c) Physician vignette, d) Coaching discussion with physician, e) Animation sequence for colonoscopy, f) Demonstration of fecal occult blood test card

Table 1Demographic Characteristics of the Focus Groups Participants^a

	Focus Groups (N=30)
Age (in years) ^b	56 (±4.5)
Country of origin	
Mexico	13 (43)
Central America	8 (26)
Caribbean	5 (17)
South America	4 (13)
Sex	
Female	16 (53)
Male	14 (47)
Speaks English	
Very Well	0
Well	9(30)
Not Well	15(50)
Not at all	6(20)
Years in the US	
<11	7 (23)
11–20	12 (40)
>20	11 (37)
Insurance	
Uninsured	20 (67)
Private	3 (10)
Public (Medicare or Medicaid)	5 (16)
Other/unsure	2 (7)
Education	
1 – 8 years	13 (43)
9–12 years	7 (23)
13+ years	10 (33)
Employment	
Working full time	7 (23)
Working part time	5 (17)
Not working	18 (60)
Household Income	
< \$10,000	18 (60)
\$10,000 – \$20,000	4 (13)
>\$20,000	3 (10)
Unsure/Declined to answer	5 (17)
Overall Health	
Excellent/very good/good	16 (53)
Fair/poor	14 (47)

Focus Groups (N=30)	
Up to date with CRC screening	
Yes	14 (47)
No	16 (53)
Comfort using a computer ^c	
Very comfortable	5 (19)
Somewhat comfortable	5 (19)
Somewhat uncomfortable	2 (7)
Don't know how to use	12 (44)
Frequency of computer use ^c	
Daily	4 (15)
1–5 times per week	5 (19)
1–2 times per month	1 (4)
Less frequently/never use	11 (41)
Unsure	3 (11)

Note. Some categories may not total 100% because of rounding.

^aData are M (\pm SD) or n (%) unless otherwise indicated.

^b1 participant had a missing value for age

^c3 participants had a missing value for frequency of computer use.

Table 2
Decision Aid Development Based on Participants' Suggestions and Thematic Findings from the Literature

Adaptation Suggested by Participants	Theme	Changes Operationalized by Researchers
1. Desire to meet a narrator	<ul style="list-style-type: none"> Personalismo (Personalism) 	<ul style="list-style-type: none"> A narrator who viewers see ("meet") and who guides them throughout the video
2. Show families	<ul style="list-style-type: none"> Familismo (Familism) Relational Interdependence 	<ul style="list-style-type: none"> 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
3. Language barriers	<ul style="list-style-type: none"> Miedo/Verguenza (Fear/Embarrassment) 	<ul style="list-style-type: none"> Videos of bilingual doctors and health professionals explaining about CRC and CRC screening
4. Afraid to talk to doctor	<ul style="list-style-type: none"> Miedo (Fear) Respeto (Respect) Power distance 	<ul style="list-style-type: none"> Video sequence modeling screening discussion with doctor Patient vignettes encouraging patients to discuss with doctor
5. Screening is embarrassing for women. Show women talking reassuringly about screening	<ul style="list-style-type: none"> Verguenza (Embarrassment) 	<ul style="list-style-type: none"> A video showing a female patient and her daughter talking to a non-Latino doctor Female patients' vignettes describing experiences with having a colonoscopy.
6. Address machismo directly	<ul style="list-style-type: none"> Machismo (Pride/Exaggerated sense of masculinity) 	<ul style="list-style-type: none"> A patient vignette where a Latino man tells other men to set aside feelings of machismo and re-evaluate their values
7. Show bilingual authoritative figures who are experts	<ul style="list-style-type: none"> Confianza (Trust/Confidence/Assurance) Language and race-concordance 	<ul style="list-style-type: none"> 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
8. Discuss cost and acknowledge uncertainty	<ul style="list-style-type: none"> Cost uncertainty 	<ul style="list-style-type: none"> A table showing cost ranges and comparing cost of FOBT and colonoscopy

Appendix

Segments and Scenes from the Spanish-language Prototype Decision Aid

Segment I Introduction	
Scene 1	A narrator welcomes the audience to the video, explains the importance of CRC and CRC screening tests, and presents FOBT and colonoscopy as well as risks and benefits of both tests.
Scene 2	A male patient talks about the importance of getting screened for one and one's family.
Scene 3	A female patient shares her experience with how CRC screening found polyps early.
Scene 4	A doctor explains what CRC is and the importance of CRC screening.
Scene 5	Animation showing parts of the colon and rectum
Scene 6	A narrator explains lifetime risks and age of getting screened for CRC screening
Scene 7	A married couple talks about husband putting off CRC screening and emphasizes importance of getting screened for one's family.
Scene 8	A narrator emphasizes importance of choosing a CRC test.
Segment II FOBT	
Scene 9	A health promoter explains about FOBT and its frequency and procedure.
Scene 10	A female patient shares her experience with having a FOBT
Scene 11	A narrator explains about having a positive test and following up with a colonoscopy.
Segment III Colonoscopy	
Scene 12	A doctor explains about the colonoscopy procedure and removal of polyps
Scene 13	Animation showing colonoscopy procedure and removal of polyps.
Scene 14	A doctor explains preparation for a colonoscopy procedure.
Scene 15	A male and female patients share their experiences with preparation before a colonoscopy procedure.
Scene 16	A doctor explains a colonoscopy procedure.
Scene 17	A video showing a patient on a hospital bed talking to a female healthcare provider as she administers anesthesia before the procedure.
Scene 18	A female patient shares about her experience with her colonoscopy procedure.
Scene 19	A health promoter explains the risk of a colonoscopy procedure.
Scene 20	A female patient shares her experience with recovery after having a colonoscopy.
Scene 21	A male patient shares his experience of choosing to do a colonoscopy over "machismo."
Segment IV Coaching (Talk to your doctor)	
Scene 22	A video showing mother and daughter talking to a doctor.
Scene 23	A narrator reviews a table that shows effectiveness, cost, time, frequency, discomfort, and risks of FOBT and colonoscopy
Segment V Stage-targeted Brochure	
Scene 24	Green, yellow, and red brochures for patients to choose one.