Developing a culturally targeted video to enhance the use of genetic counseling in Latina women at increased risk for hereditary breast and ovarian cancer

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Abstract

Disparities for genetic cancer risk assessment (GCRA) for hereditary breast and ovarian cancer (HBOC) persist between Latina and non-Hispanic Whites. There are few tested culturally targeted interventions. We developed a culturally targeted video to enhance GCRA uptake in at-risk Latinas. Interviews with healthcare providers ($n = 20$) and at-risk Latinas ($n = 20$) were conducted as formative research to inform the development of the video. Findings from the formative research, health behavior conceptual models, and evidence-based risk communication strategies informed the messages for the script. Then, we conducted a focus group with at-risk Latinas ($n = 7$) to obtain feedback for final refinement of the script. The final video was piloted for acceptability and potential dissemination in a sample of Latino community health workers (CHWs) ($n = 31$). Providers and at-risk Latinas suggested using simple language and visual aids to facilitate comprehension. Participants in the focus group identified areas for further clarification (e.g., cost). The result was an 18-min video that illustrates “Rosa’s” story. Rosa learns about HBOC risk factors and overcomes barriers to attend genetic counseling. CHWs reported high overall satisfaction with the video ($M = 9.61$, $SD = .88$, range 1–10). A culturally targeted video has the potential to reach underserved populations with low literacy and English proficiency.

Keywords Hereditary breast and ovarian cancer · Genetic counseling · Latinas · Health disparities · Intervention, translational genomics, health communication

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Introduction

Despite national priorities to increase genetic cancer risk assessment (GCRA) among racial and ethnic minorities at risk of hereditary breast and ovarian cancer (HBOC), disparities persist between Latina and non-Hispanic Whites (Childers et al. 2018; Dean et al. 2015; Hall et al. 2009; Levy et al. 2011). Women with *BRCA1* and *BRCA2* mutations have a greatly elevated lifetime risk of breast and ovarian cancer, and breast cancer survivors who carry a *BRCA1* or *BRCA2* mutation are at substantially increased risk for developing a contralateral breast cancer compared with non-carriers (Mavaddat et al. 2013; Molina-Montes et al. 2014). Moreover, among certain subsets of women with breast cancer, Latinas have the highest rate of *BRCA1* mutations second only to Ashkenazi Jews (Weitzel et al. 2013). Yet, Latinas are less likely to use GCRA compared with non-Hispanic Whites (Childers et al. 2018; Dean et al. 2015; Hall et al. 2009; Levy et al. 2011). Barriers to GCRA include access, language, limited knowledge and awareness, low health literacy and numeracy, competing priorities, and emotional concerns (Hurtado-de-Mendoza et al. 2018; Kinney et al. 2010; Pagán et al. 2009; Sussner et al. 2013; Sussner et al. 2010; Vadaparampil et al. 2006). Importantly, even when at-risk Latinas attend genetic counseling, there are important gaps in communication that can lead to misunderstandings of the risk information (Joseph and Guerra 2015; Joseph et al. 2017).

Ensuring that GCRA information is understandable and culturally appropriate is paramount to advancing translational efforts and reducing utilization gaps among at-risk Latinas. Several studies have documented at-risk Latinas' preferences for interventions and education materials in Spanish that include common words, visual aids (e.g., pictures, drawings), narrative or story format, and the exclusion of medical jargon (Gammon et al. 2011; Joseph et al. 2010; Kinney et al. 2010; Sussner et al. 2010). Few education interventions have been developed for at-risk Latinas (e.g., Joseph et al. 2010; Sussner et al. 2010; Vadaparampil et al. 2018). To our knowledge, these interventions have not yet been formally tested.

Increasing evidence suggests that narratives can be an effective strategy for cancer-related communication (Borrayo et al. 2017; Kreuter et al. 2007; Larkey and Gonzalez 2007; Murphy et al. 2015). Narratives are a “representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit or explicit messages about the topic being addressed” (Kreuter et al. 2007, p.222). Narratives present events and characters vs. explicit arguments and lists of facts. Narratives can increase the relevance of the messages through an individual's transportation to the story and identification with characters. Characters can model desirable behaviors and overcome barriers, which can result in increased self-efficacy (Green 2006). A recent randomized controlled trial found that a culturally targeted

narrative film was more effective than a non-narrative film in increasing knowledge and uptake of cervical cancer screening among Mexican Americans (Murphy et al. 2015). Importantly, knowledge increased regardless of health literacy levels (Moran et al. 2016) and the narrative film ameliorated screening disparities between Mexican Americans and non-Hispanic Whites (Baezconde-Garbanati et al. 2014).

Narrative films may also be a particularly appealing medium to deliver health information to populations with low health literacy and populations that value oral communication (Green 2006; Kreuter et al. 2007). Videos and social media are more contemporary strategies for health education compared with prior educational interventions that used only static print. These new dissemination approaches facilitate the reach and impact of interventions (Brownson et al. 2018).

The goal of the present study was to develop a culturally targeted narrative film to enhance the use of GCRA services in Latina women at risk of HBOC based on their personal or family history of cancer. Given the scarcity of HBOC materials in Spanish, the intended audience was Spanish-speaking Latina women (not specific to a country or region in Latin America) with low health literacy and limited English proficiency.

The video was developed by a multidisciplinary team that included scholars with diverse backgrounds (e.g., psychology, epidemiology, genetics, oncology). The research team collaborated with the production company “Crash of Rhinos” from the National Conservatory of Dramatic Arts (NCDA) in Washington DC. In this paper, we (1) describe how we used theoretical conceptual models, evidence-based risk communication strategies, and formative research to develop the video messages, (2) describe formative research from interviews with providers and at-risk Latinas, (3) describe a pilot to assess the acceptability and potential dissemination of the video in a sample of Latino community health workers, and (4) describe the partnership between researchers and the National Conservatory of Dramatic Arts (NCDA), the process of and lessons learned during video development. This study is part of a larger single-arm feasibility study that will pilot the impact of the culturally adapted video plus navigation on at-risk Latinas' uptake of genetic counseling as well as potential mediators such as knowledge and self-efficacy.

Methods

Overview

Georgetown University Institutional Review Board approved the study procedures. First, we conducted qualitative formative research and analyzed the data. Then, we used the findings from the qualitative analysis, tenets from two health behavior conceptual models, and evidence-based risk

communication strategies to inform the development of the messages for the video script. The researchers and the NCDA developed the script iteratively and held a staged reading focus group to make final refinements. Then, we conducted the production and post-production of the video. Finally, we assessed the acceptability and potential dissemination of the video in a sample of 31 Latino community health workers (see Fig. 1 for an overview).

Theoretical framework

Conceptual models We used tenets from Social Cognitive Theory (SCT) (Bandura 2004) and from the theory of planned behavior (TPB) (Ajzen 1991) to identify relevant constructs to target. SCT (Bandura 2004) emphasizes the use of observational learning through media to increase self-efficacy by having peers and well-respected sources model healthy behaviors. SCT highlights environmental influences in overcoming barriers and enabling behaviors. The TPB (Ajzen 1991) identifies the intention to perform a behavior as the most proximal determinant of behavior. Attitudes (positive/negative evaluations of the behavior), subjective norms (perceived social pressure to perform the behavior), and perceived control

(confidence in performing the behavior) are influenced by beliefs and independently impact behavioral intentions. Perceived control also exerts a direct impact on behavior. We also considered cultural and social contextual factors that provide important nuances to some theoretical constructs from health behavior models (Burke et al. 2009) that could be relevant for Latina GCRA uptake, including *familismo* (central role of the family), respect (importance of respecting others, especially in positions of authority or the elderly), and religiosity (Penchaszadeh 2001).

Formative data to inform the development of the video

Data collection

Following a mental models approach (Morgan 2002), we conducted interviews with expert healthcare providers and at-risk Latina immigrants. Step 1: Interviews with experts. We interviewed 20 healthcare providers (e.g., genetic counselors, navigators) recruited through snowballing and discipline-specific listservs. The interviews gathered the experts' perceptions about essential knowledge to make informed decisions

Fig. 1 Flow chart. ^aSocial cognitive theory. ^bTheory of planned behavior

Note: ^a Social Cognitive Theory, ^b Theory of Planned Behavior.

about participating in GCRA, Latina's motivators and barriers to participate in GCRA, and suggestions to inform the development of the video. Step 2: Interviews with at-risk Latinas. We interviewed 20 Latinas, including women personally affected ($n = 10$) with cancer and unaffected, but with a family history of cancer ($n = 10$) who met NCCN 2015 criteria to be considered at-risk of HBOC. Interviews followed a funnel structure, starting with general open-ended questions about HBOC and GCRA. Then, follow-up questions queried women about the key knowledge revealed by the healthcare providers which had not been spontaneously mentioned by the interviewee. Interviews identified the words women used to discuss HBOC and GCRA, facilitators and barriers, knowledge gaps, cultural and contextual factors, and suggestions for the video. Detailed findings about the providers' and Latinas' interviews have been described elsewhere (Gómez-Trillos et al. 2018; Hurtado-de-Mendoza et al. 2018). In this paper, we present the study findings pertaining the video suggestions and explain how the other main findings (e.g., barriers and facilitators) informed the development of the script.

Analysis

All the interviews were recorded and transcribed. Following the Consensual Qualitative Research Framework (Hill et al. 2005), two members of the research team read three interviews and independently developed a list of emerging codes. Then, they met to reconcile the codes and develop a master codebook with definitions. Codes were further refined in an iterative process throughout the coding. Each interview was coded by two team members independently. Then, they met to reconcile the codes. Discrepancies were solved by consensus. Data was entered in Dedoose (SocioCultural Research Consultants 2016), a qualitative analysis software.

Methods to use formative data, theoretical constructs, and evidence-based risk communication strategies to inform the video script

As a first step, two members of the research team met to identify important theoretical constructs, evidence-based risk communication strategies, and the most prominent themes from our formative work. Then, we developed a document that included: the description of the target audience, the key health information to include in the video, knowledge gaps, words and concepts that at-risk Latina were familiar with, main motivators and barriers to address, cultural aspects to consider, and the main conceptual constructs. Additionally, the research team outlined potential scenes and described how each scene could target the relevant themes and theoretical constructs. This document was discussed and further refined in a series of meetings with other members of the research team. Next, members of the research team met with the

scriptwriter and producer from the NCDCA to discuss the formative data and brainstorm the script. Nan Ficca, from the NCDCA, wrote the initial script. The script underwent an iterative process with feedback and discussion between the researchers and the scriptwriter. Once finalized, the script was translated into Spanish.

Methods to obtain feedback on the video script

Following established methods for health education video development (Baezconde-Garbanati et al. 2014), we conducted a staged focus group at the NCDCA with the script developed between researchers and scriptwriter. Actors read the script aloud for seven at-risk Latinas (four affected with breast cancer, two affected with ovarian cancer, one unaffected but at-risk based on family history of cancer). Then, two researchers facilitated a focus group to elicit feedback about messages, clarity, characters, duration, and suggestions for changes. We used participants' feedback to refine the script.

Methods to obtain feedback on the video

The video was showcased at a workshop from a program called "ÁRBOLES Familiares" ("Genealogical Trees", in English) (Graves et al. 2018). The goal of this program is to train community health workers, patient navigators, and promotoras that actively work with the Latino community in the USA to identify and refer Latina women who are at-risk of HBOC to GCRA services. Thirty-one community health workers watched the video and then filled out a survey. The survey captured sociodemographic data (e.g., age, ethnicity), their role (e.g., patient navigator), experience working with at-risk Latinas (e.g., length of time working with at-risk Latinas), acceptability, and potential dissemination. The 13-item acceptability scale gathered individuals' perceptions about different aspects of the video. Four items assessed the general perception of the video (e.g., overall satisfaction,) on a 10-point Likert scale (ranging from 1 "not at all" to 10 "highly"). The higher the score, the higher level of satisfaction. Nine items evaluated participants' degree of agreement with statements about specific aspects of the video such as the video length, information clarity, and potential usefulness for at-risk Latinas. The 5-point Likert response scale ranged from 1 "strongly disagree" to 5 "strongly agree." The survey also included questions about potential dissemination of the video including potential channels for dissemination (e.g., YouTube, DVD), settings (e.g., hospitals, community centers), and context to watch the video (e.g., alone, with relatives). Participants could select multiple choices from the list and add others if needed. Finally, three open-ended questions asked about how the video could be useful for the Latino community, the things they liked the most from the video, and suggestions for improvement. Data was entered in SPSS

version 25. We used descriptive statistics to analyze the survey, and content analysis to summarize the feedback from the open-ended questions.

Results

Results on formative data

Providers ($n = 20$) and at-risk Latinas ($n = 20$) made several recommendations about how to develop the video (see Table 1). Overall, participants responded favorably to the idea of a narrative-based YouTube video about HBOC and GCRA targeted to Latinas. Both Latinas and providers said it would be important to include a multigenerational family, show social support within the family, and give an example of good family communication to help address stigma. They suggested using relatable situations (e.g., actors should not look like “supermodels”), using simple language and limiting jargon, using visual aids, and keeping the tone positive. Both groups pointed out common misconceptions about HBOC and GCRA among Latinas. Providers suggested the video could address anxiety and fear about genetic counseling and reframe guilt by emphasizing that genetic test results can positively inform family members. Latinas said the video should be somewhat dramatic and include humor but not be sad, dark, or scary.

Findings about barriers and facilitators, knowledge gaps, and cultural and contextual factors have been described elsewhere (Gómez-Trillos et al. 2018; Hurtado-de-Mendoza et al. 2018). Briefly, the main motivators for at-risk Latinas to participate in GCRA were informing the risk of family members, informing prevention and treatment decision, and following doctor’s recommendations. Prominent barriers included cost/insurance, suboptimal referrals, low awareness about HBOC and GCRA, emotional concerns, language, and low health literacy and education. Providers, especially patient navigators, also highlighted challenges identifying resources to cover risk management and surveillance care for women following receipt of a positive genetic test result, given that these resources vary by location and state regulation. In relation to knowledge gaps, there was a low awareness about genetic counseling and limited knowledge about age at diagnosis being a risk factor for HBOC. Most women were unfamiliar with *BRCA1/2* genes and with the concept of genetic mutation. In fact, they tended to confuse the word “mutation” with “mutilation.” Our formative work also indicated that at-risk Latinas had challenges differentiating between gynecological cancers (e.g., cervical, ovarian, uterine) and held the misconception that the Pap smear was a screening test for ovarian cancer. Important cultural and contextual factors included familismo, religiosity, respect, stigma around cancer, and competing priorities. For instance, Latinas described

stigma around cancer, especially in older generations and rural populations, which could hinder the process of obtaining accurate family history. Our formative research suggests that out of respect (cultural value of *respeto*) Latina women tend to follow doctors’ recommendations and they are used to more vertical relationships between doctors and patients. Thus, the non-directiveness mandate of genetic counseling can be confusing. One recommendation was to use a more directive approach while highlighting that the testing decision is theirs (see Hurtado-de-Mendoza et al. 2018).

Results on how the formative data, conceptual models, and evidence-based risk communication strategies informed the video script

The video script was informed by tenets from two conceptual models, evidence-based risk communication strategies, and findings from the formative data (see Table 2).

Formative data

The narrative format allowed us to represent important aspects of HBOC and GCRA participation and include characters who modeled proactive behaviors (e.g., going to counseling). As suggested in the formative research, we depicted a multi-generational family and modeled open communication between relatives. Additionally, having characters from different generations allowed us to illustrate generational differences and provide characters with whom individuals from different ages and education could identify. The tone of the video is positive and optimistic rather than scary and it incorporates some humor.

Selecting the key scientific messages Rather than presenting a comprehensive list of HBOC risk factors, we selected three main risk factors based on the input from the key informants: (1) being diagnosed with breast cancer at age 50 or younger, (2) being diagnosed with ovarian cancer at any age, and (3) having a family history of certain types of cancers. In relation to management strategies, we mentioned screening and risk-reducing surgeries as options to effectively manage risk. We did not provide specific information about the types of screening (e.g., mammogram) or risk-reducing surgeries (e.g., salpingo oophorectomy) since it was out of scope for this study. The goal of the video was to increase genetic counseling uptake, during which individuals receive comprehensive information about risk factors and risk-reducing strategies (Resta et al. 2006).

Balancing accuracy and understanding We sought to balance scientific precision and ease of understanding for the target population. Initially, all the characters in the video referred to a “gene alteration that increases the chances of developing

Table 1 Video suggestions from the formative research

Themes	At-risk Latinas (<i>n</i> = 20)	Providers (<i>n</i> = 20)
Characters	<ul style="list-style-type: none"> •Include the doctor and genetic counselor. •Main character should be a woman, affected (perhaps a survivor), and a mother. •Portray a multigenerational family, and include teenagers and kids. •Make characters real and relatable: look Latina, speak Spanish, not look like “supermodels.” 	<ul style="list-style-type: none"> •Multigenerational family •Use characters other than a multigenerational family and doctor, such as a supporting member of the clergy.
Communication	<ul style="list-style-type: none"> •Give some examples of communication about genetic counseling and testing within the family and with the doctor. •Include the family and show examples contrary to cultural taboos against open communication in the family. 	<ul style="list-style-type: none"> •Address how to start the conversation with the family and the doctor, why genetic testing is important, who should have genetic counseling, and which are the risks or “red flags” that could indicate increased risk. •Be mindful of word connotations and cultural sensitivity.
Emotions	<ul style="list-style-type: none"> •Make the video with a sense of humor rather than being dark, sad, and scary. •Women may experience anxiety while waiting for the results, but genetic counseling is often helpful to ease the anxiety. 	<ul style="list-style-type: none"> •Stress scientific advancement can give hope for better outcomes. •Reframe guilt in respect to their children by portraying genetic testing results as a gift to their family to be proactive. •It is common for women to feel overwhelmed, scared, anxious, or guilty about genetic counseling. •Latinas often become anxious quickly, but usually this anxiety leads them to want to act.
Facilitate Understanding	<ul style="list-style-type: none"> •Make the video in Spanish •Use simple, everyday language •Avoid medical jargon. <p>Use visuals, such as drawings.</p>	<ul style="list-style-type: none"> •Keep the information simple and broad. •Avoid jargon. Use relatable analogies instead. •Use visual aids and natural frequencies or whole numbers when explaining risk. •Communicate information clearly, in a simple and general way
Format	<ul style="list-style-type: none"> •Telenovela style using real stories. •Use common language in terms of words and expressions used across Latin American countries. •Utilize familiar spaces, such as a Church or a kitchen. •Deliver information in a positive way. 	<ul style="list-style-type: none"> •Set the video in a relatable and comfortable atmosphere. •Characters should use warm and friendly tone. •Use phrases such as “knowledge is power,” “saber es poder,” and other empowering sentences that reinforce the idea that information is power.
Information	<ul style="list-style-type: none"> •Latinas want to learn from survivors’ experiences and testimonies. •Where to find reliable information •Differences between breast cancer and HBOC •What is genetic testing •What to expect from GCRA •Insurance and assistance programs •Emphasize that the test does not hurt 	<ul style="list-style-type: none"> •What is genetic counseling, the process, and its benefits •Keep the information broad, and vague because 1) all patients are different and counseling adapts to them, so making a very specific video would not appeal the entire population we intend to target, and 2) technology and science are always changing and the video could become obsolete easily. •Highlight signs that might indicate hereditary cancer in the family (e.g., cancer before 50 years old, ovarian cancer). •Reiterate the availability of genetic counseling and testing services, and the importance of bringing it up with their doctors. •Clarify that genetic counselors are there to help and that there are many options available to them. •Address cancer stigma in older generations.
Misconceptions	<ul style="list-style-type: none"> •Men cannot have breast cancer, are not affected by the BRCA mutation, and cannot pass on the gene. •Everyone has the same risk of HBOC •Genetic testing results are a diagnosis of cancer. •If genetic testing results are positive, they will be forced to remove their breasts/ovaries. •Genetic counseling is like going to a psychologist. •It is useless to receive genetic counseling or testing if you already had cancer. •Being depressed increases the chances of HBOC. •PAP smears are enough screening for HBOC. •The results of genetic testing are always certain. •“Mutation” means “mutilation,” “amputation” or “metastasis.” •Cancer is contagious and sexually transmitted. 	<ul style="list-style-type: none"> •Genetic counseling is related to psychological counseling. •Having genetic counseling means you have to do genetic testing, and then will probably need to have a mastectomy. •Genetic testing is diagnostic. •Cancer is always fatal and it is contagious •Men cannot have or pass altered genes linked to HBOC •Cancer was caused by some physical injury, something they did wrong, or as a punishment for atonement. •Genetic counseling is a waste of time if they already had cancer. •Genetic testing is too expensive. •Cancer is not to be talked about, it is shameful.
Social support	<ul style="list-style-type: none"> •Portray support from the family to the patient. 	<ul style="list-style-type: none"> •Include examples of social support (e.g., going with them to counseling, taking notes, asking questions, helping look for resources). •Include tips for other family members or friends on how to support the person who is getting the exam.

Table 1 (continued)

Themes	At-risk Latinas (<i>n</i> = 20)	Providers (<i>n</i> = 20)
Values	<ul style="list-style-type: none"> •Emphasize that the test can save their life and their families' lives. 	<ul style="list-style-type: none"> •Have someone from the family support by doing extra research. •Address the benefits of genetic information not only for the patient, but also for the family. •Include figures of authority that Latina patients might know and trust to support their values and their beliefs (e.g., doctors).

cancer.” However, while accurate, this level of precision in speech made the script harder to understand and did not reflect how most Latinas colloquially describe HBOC. Thus, we decided to maintain clinical terminology for the characters representing healthcare providers (i.e., genetic counselor) and use simplified language for other characters by omitting the word “alteration” (e.g., “genes that increase the chance of developing cancer”), better emulating natural speech in our target population.

Knowledge gaps Data from our formative phase indicated that at-risk Latina women were unfamiliar with genetic counseling and that unfamiliarity caused them some feelings of anxiety and fear. Therefore, we depicted a genetic counseling session in the video. In addition, we stressed being diagnosed with breast cancer before age 50 as an important risk factor for HBOC, as our formative research suggested that Latinas were largely unaware of this risk factor. Given the confusion between “mutation” and “mutilation,” and the potential of “genetic change” to trigger the misconception that the genetic test results can change, we opted to use “gene alteration” throughout the video. We decided not to mention *BRCA1/2* specifically to be responsive to women’s preference to avoid medical jargon and to keep the information general to avoid potential confusion with other genes associated with hereditary cases of breast and ovarian cancers. The genetic counselor in the video used a drawing of the female reproductive system to illustrate the difference between the cervix and the ovaries. We also had some characters voice the misconception about Pap smears being a screening test for ovarian cancer followed by a correction with appropriate information.

Facilitators and barriers The video targeted the most prominent facilitators and barriers to GCRA uptake from the formative research. *Family*: Given that gaining information about relatives’ cancer risk was one of the main motivators for GCRA participation, both the doctor and genetic counselor highlight the relevance of information for the family. The main character, Rosa, chooses to get genetic testing to protect the health of her family (in addition to informing risk-reducing options for herself). Rosa’s family is very supportive. The video also targets several barriers. *Cost*: The video includes information about lab assistance programs. *Language*

barriers: We developed the video in Spanish and included an interpreter in the genetic counseling session to show that language barriers can be overcome.

Cultural and contextual factors *Stigma*: We targeted stigma through Rosa’s mother. She voiced some of the stigma related to cancer in her native country in Latin America and clarified some of the misconceptions that lead to stigma. *Respect*: In the video, the genetic counselor is more directive than usual in her recommendation for testing, given that non-directiveness can potentially confuse Latinas, giving them a sense that it is not important. *Competing priorities*: One of the characters (Paula, Rosa’s friend) exemplifies the types of competing priorities Latina women face (e.g., financial struggles being a single mother), which can prevent them from seeking health services. However, Rosa appeals to other cultural values (*familismo*) to encourage her friend to seek genetic counseling.

We included popular sayings that could resonate with the Latino community. Some of the sayings were extracted from the interviews with providers and with at-risk Latinas (e.g., “God gives the hardest battles to the bravest warriors”). We also used some English words and expressions to reflect code switching (alternating different languages in a conversation) evident in the at-risk women who participated in the formative phase.

Conceptual models

Following the tenets from the SCT, we developed a narrative video with Latino actors representing peers to enhance observational learning. The main character, Rosa, serves as a role model on how to overcome barriers to GCRA uptake to increase self-efficacy. To address environmental influences in overcoming language barriers, we decided to film the video in Spanish. To overcome access barriers, we partnered with two community-based organizations that have existing relationships with service providers and clinics that provide free or reduced cost care to women without insurance. The role of patient navigators was to identify potentially eligible participants, identify free or low-cost GCRA services, schedule the genetic counseling sessions, and navigate women with positive genetic test results to no cost or low-cost services for risk management and surveillance. We also targeted tenets from

Table 2 Formative research, conceptual framework, evidence-based risk communication strategies informed messages from the video

Construct		Messages
Facilitators	Inform family members' risk	<ul style="list-style-type: none"> • Doctor and counselor stress that the information is relevant for relatives • Rosa decides to do the testing for her family • Rosa encourages Paula to ask her doctor because it would be a gift to Paula's daughter
	Inform prevention and treatment decisions for self	<ul style="list-style-type: none"> • Doctor informs about the existence of effective surgeries and screening
Barriers	Follow doctor's recommendations	<ul style="list-style-type: none"> • Doctor suggests visiting a genetic counselor
	Cost and insurance	<ul style="list-style-type: none"> • Rosa tells Diego about the availability of assistance programs and low-cost testing
	Limited awareness/knowledge	<ul style="list-style-type: none"> • The video models a genetic counseling session • The video models the duration and procedure of a genetic test sampling • The video explains HBOC, risk factors, and genetic counseling and testing.
	Suboptimal referral	<ul style="list-style-type: none"> • Rosa encourages Paula to ask her doctor in her next visit
	Language	<ul style="list-style-type: none"> • The video is in Spanish • The video models availability of interpreters
	Emotions	<ul style="list-style-type: none"> • Addresses emotional concerns • Guilt: emphasizes that we have no control over what genes are passed to our children. • Targets positive emotions: Reframes guilt as pride, because the information can help their family. • Fear: explains the process of genetic counseling and testing. Clarifies that it is not painful. • Risk information is followed by messages to increase self-efficacy to avoid potential backlash of eliciting fear
	Health literacy	<ul style="list-style-type: none"> • Uses simple language standard to all Latin American countries • Defines complex medical terms • Focuses on short key messages • Avoid concepts that are too technical (BRCA1/2)
Knowledge gaps	Genetic test is a cancer diagnostic test	<ul style="list-style-type: none"> • Clarifies and reiterates that the test is to inform the chances of developing cancer in the future
	"Female cancers:" confusion between ovarian, cervical, and uterine cancer	<ul style="list-style-type: none"> • Shows an illustration of the female reproductive system to clarify, while the genetic counselor explains it.
	Pap smear is a screening for ovarian cancer	<ul style="list-style-type: none"> • Clarifies that the pap smear is a screening for cervical cancer, and that there is not a good screening for ovarian cancer
	The word "mutation" is unfamiliar and confused with "mutilation"	<ul style="list-style-type: none"> • Uses the word "genetic alteration"
	HBOC alterations only transmitted through the father side	<ul style="list-style-type: none"> • Explains that HBOC alterations are inherited through the mother and the father side • Men can also have breast cancer
Cultural and contextual factors	Stigma and taboo around cancer	<ul style="list-style-type: none"> • Clarifies that cancer is not contagious • Models communication about HBOC and GCRA • Rosa's mother exemplifies stigma in older generations
	Religiosity and spirituality	<ul style="list-style-type: none"> • Uses common expression: "thank God"
	Other cultural targeting	<ul style="list-style-type: none"> • Use of popular sayings
	Competing priorities	<ul style="list-style-type: none"> • Encourages the need to take care of oneself first in order to be able to take care of the family • Rosa's neighbor exemplifies competing priorities (single mom)
	Respect for doctors	<ul style="list-style-type: none"> • Models more clear recommendations from the doctor and genetic counselor
Other theoretical constructs	Vertical relations between doctors and patients	
	Potential confusion with non-directedness.	
	Attitudes	<ul style="list-style-type: none"> • Information about the benefits of participating in GCRA
	Subjective norms	<ul style="list-style-type: none"> • Rosa's family approves of and supports her participation in counseling
	Perceived control	<ul style="list-style-type: none"> • The characters in the video discuss several facilitators and barriers for GCRA uptake. • Rosa becomes a role model for a friend regarding how she overcomes the barriers to participate in counseling.

the theory of planned behavior. For instance, to target subjective norms, Rosa's family approves of her participation in genetic counseling. Table 2 shows how other constructs were addressed in the video.

Evidence-based risk communication strategies

We framed messages using evidence-based risk communication strategies: focusing on the key risks/benefits, using visual aids to facilitate understanding of complex information, using natural frequencies vs. percentages to enhance comprehension of numerical risk information, and directly addressing misconceptions by stating the misconception followed by the correct information (Fischhoff 2012; Morgan 2002).

Results on piloting of the video script

Participants in the focus group reported that they enjoyed the script reading. They also liked that the script was in Spanish and that the information presented was medically accurate but easy to understand for everyone. Moreover, they identified with the characters in the video and expressed interest in sharing it with family members and friends. When asked about the length, participants thought the duration was ideal, reporting that they were engaged the entire time. Participants suggested that the video should emphasize the lack of effective screening for ovarian cancer and the importance of genetic testing for prevention. All participants agreed that there should be more emphasis on the availability of low-cost genetic testing options for those without insurance and that information about additional resources should be provided at the end of the video. Some participants voiced a desire to include broader information about cancer such as symptoms and surgeries. Lastly, they strongly suggested having a straightforward title for the video that contained the words “genetic,” “cancer,” or “hereditary” so it would be easy to find when searching online.

Based on the focus group findings, we added more information about the lack of effective screening for ovarian cancer in the genetic counseling scene along with further information on cost and insurance. We also included a list of additional resources in the closing credits. In the final scene, we further emphasized the importance of genetic testing by adding explicit encouragement in the conversation between Rosa and her friend Paula. Finally, we decided on the title of the video based on focus group participants' suggestions (see Table 3).

Description of the video

The 18-min video, “Hereditary Cancer? Rosa visits a genetic counselor”, uses a culturally targeted narrative approach to convey facts about HBOC and GCRA. The main character

of the film is Rosa, who was diagnosed with breast cancer at 49 years old. Scene summaries are presented below.

Scene 1: Rosa has a medical appointment with a new oncologist one year after her cancer diagnosis. The doctor explains that her young age at diagnosis indicates that her cancer could be hereditary and recommends that she should see a genetic counselor. Scene 2: At home, Rosa shares the information about genetic counseling with her husband. They discuss some barriers (e.g., time, cost) but Rosa's husband is supportive. Scene 3: While having dinner, Rosa's family (two grown children, husband, sister) discuss what Rosa learned about genetic counseling and testing. Scene 4: Rosa calls her mother, who lives in Latin America, to find out about her family history of cancer. Rosa's mother voices the difficulties of having accurate information due to the stigma around cancer and the limited access to medical specialists. Scene 5: Afterward, Rosa talks to her husband and decides to see the genetic counselor. Her daughter offers to interpret if necessary. Scene 6: Rosa and her daughter attend a genetic counseling appointment. The counselor, through the interpreter, provides information about HBOC and genetic testing and addresses some common misconceptions. Rosa decides to do the test. Scene 7: one month after the genetic counseling session, Rosa meets a friend whose mother died from ovarian cancer, Rosa shares with her the information she learned at the counseling session and encourages her to see a genetic counselor. They discuss challenges that her friend has (e.g., competing priorities). However, when Rosa stresses the importance of this information for the family, her friend agrees and mentions that she plans to ask her doctor at her next appointment.

Results on piloting of the video

Participants ($n = 31$) had an average age of 46 years ($SD = 16.99$), all self-identified as Hispanic or Latinos, most were female (90.3%), and worked as patient navigators (29%) or community outreach workers (25.8%). The video's general acceptability was very high. Participants reported high ratings for overall satisfaction, how much they liked it, enjoyed it, and considered it to be interesting (all means > 9.6). Most participants strongly agreed or agreed that the length was adequate (80.7%), that the information presented was very helpful (100%), that the video could be useful for the Latina community (96.8%), and that they would share the video with women at-risk of HBOC (100%). The highest endorsed channels for dissemination were Facebook (90.3%) and YouTube (87.1%). The highest endorsed settings were community centers (100%), churches (96.8%), and hospitals (80.6%). Most participants (90.3%) considered that the best ways to watch the video would be with relatives, followed by watching with other women at-risk of HBOC (71.0%), with friends (71.0%), and lastly by oneself (41.9%) (see Table 4).

Table 3 Focus group findings (n = 7)

Findings		
Positive feedback	Suggestions	Implications
<p>Content</p> <ul style="list-style-type: none"> •The script was informative. It contained a lot of good/useful information. •Participants learned the distinction between cervical and ovarian cancers. Further learned that PAP smears do not detect ovarian cancer. •Really liked that the information conveyed was medical and accurate, because there is a need to educate the Latino community to encourage going to the doctor. •The script conveyed information that would be beneficial for everyone, even if they are not affected by cancer. •It was clear that people may be at-risk for hereditary cancer even if they have not had cancer themselves and that the genetic test is appropriate. •Portrays the older generations well, with the taboo and guilt. <p>Language</p> <ul style="list-style-type: none"> •The script was clear, well-done, and well directed to the Latino community. •Language was easy to understand. Some of the most complicated words were explained in the script in a clear way. <p>Format</p> <ul style="list-style-type: none"> •Believed that a video is a good way to address misconceptions •They thought the length was ideal, not too long and not too short. They did not find it overwhelming. It contained enough information to be complete and clear, without getting boring. •Liked the telenovela style because “that is what people like” <p>Characters</p> <ul style="list-style-type: none"> •Felt identified with the family scene. Claimed it was something that everyone could relate to, regardless of their country of origin. •Liked that the characters showed that it is possible to break down old taboos about cancer. •Felt very identified with the characters, the dialogue, the family scene, the husband, the food. Different components of the video affected each of them differently. Liked that there was a character who was not herself affected 	<p>Content</p> <ul style="list-style-type: none"> •Emphasize that there are no good screenings for ovarian cancer, which is why the genetic test can be very valuable for prevention. •Have more emphasis on the different options of preventive surgery and management if genetic test is positive. •Some participants wanted to know more about cancer symptoms. •Emphasize more that there is a way to get genetic testing despite high costs and lack of insurance. There are options for everyone, especially important because for Latinas, finances are a big barrier and it creates fear. •Crucial to put resources at the end of the video, because people who are interested will need to know how to follow up. <p>Dissemination and implementation</p> <ul style="list-style-type: none"> •Not everyone will have access to YouTube. In the Latino community, a lot of information is communicated by word of mouth. •Promoting the video in key locations will be important. Many young Latinas are too busy working, resting, and taking care of their kids to watch TV/YouTube (e.g., promote in Churches). •Will be harder to reach people who have not been affected. <p>Title</p> <ul style="list-style-type: none"> •Participants suggested that the title should be straightforward and clear. The title must include keywords, for example “genetic”, because that way it will be easy to find. It was also suggested that the title be in the form of a question (“Is my cancer hereditary?”). 	<ul style="list-style-type: none"> •Added more details in the scene with the genetic counselor, explaining the lack of good screening for ovarian cancer. •Cancer symptoms and management options were not elaborated on because it was considered beyond the scope of the video. •Added a sentence to the final script to address cost and insurance. •Added more encouraging words from Rosa to Paula in the final scene to outweigh the pros of genetic testing against the cost and other potential barriers. •Following the recommendations from the focus group, the final title of the video is “Hereditary Cancer? Rosa visits a Genetic Counselor” (in Spanish <i>¿Cáncer Hereditario? Rosa visita a un consejero genético</i>).

In relation to the potential usefulness, participants praised the potential impact of the video to increase awareness, especially in communities with low health literacy. Providers also noted that the video could be useful because it presents the information in a way that is easy to understand, it is culturally targeted, it includes characters that the community can identify with, and it targets important barriers for this community: “I

think (the video) is culturally sensitive and presents language appropriate for people with low level education.”

Providers reported several positive aspects of the video including the fact that the video is in Spanish, the clarity of the information presented, the story line and the dramatization, the involvement of the family, and modeling communication among relatives: “I liked that the lead character was

Table 4 Community health workers ($n = 31$)

Community health workers	
Demographic characteristics	
Age M (SD)	46 (16.99)
Gender N (%)	
Female	28 (90.3)
Male	3 (9.7)
Ethnicity N (%)	
Latinos	31 (100)
Race N (%)	
Black	2 (6.5)
White	13 (41.9)
More than one race	4 (12.9)
Prefer not to answer	6 (19.4)
Time working with at-risk Latinas N (%)	
Less than a year	7 (22.6)
1–5 years	14 (45.2)
5–10 years	5 (16.1)
More than 10 years	4 (12.9)
Other (not working with at-risk Latinas)	1 (3.2)
Provider roles N (%)	
Patient navigator	9 (29)
Psychologist	1 (3.2)
Social worker	2 (6.4)
Community outreach	8 (25.8)
Community health worker	4 (12.9)
Other	7 (22.6)
Percentage of Latinos seen per week N (%)	
60–80%	8 (25.8)
81–100%	16 (51.6)
Missing	7 (22.6)
General Acceptability (M ,SD) (scale 1–10)	
Interesting	9.68 (.79)
Like	9.61 (.88)
Enjoyable	9.65 (.87)
Overall satisfaction	9.61 (.88)
Acceptability-specific (M ,SD) (scale 1–5)	
Adequate length	4.32 (.86)
Information easily understandable	4.74 (.44)
Helpful information	4.9 (.30)
Appropriate quantity and detail of information	4.74 (.44)
Learned a lot of information about HBOC	4.29 (.90)
Information useful to understand risk	4.65 (.66)
I had trouble understanding the information	1.54 (1.20)
Would share the video with at-risk women	4.84 (.37)
Video would be useful for the Latina community I work with	4.84 (.58)
Dissemination channels (N , %)	
Facebook	28 (90.3)
YouTube	27 (87.1)
WhatsApp	14 (45.2)
Instagram	11 (35.5)

Table 4 (continued)

Community health workers	
Twitter	5 (16.1)
Other social media	2 (6.5)
DVD	8 (25.8)
Other platforms (e.g., TV)	8 (25.8)
Settings for watching the video	
Community centers	31 (100)
Church	30 (96.8)
Hospitals	25 (80.6)
Schools	24 (77.4)
Other places (e.g., health fairs, support groups, community clinics)	15 (48.4)
Context for watching the video	
With relatives	28 (90.3)
With other at-risk women	22 (71.0)
With friends	22 (71.0)
By oneself	13 (41.9)
Other (e.g., with health specialist)	5 (16.1)

able to rephrase the information in her own words and was shown sharing it with friends and family.”

The suggestions to improve the video included making it longer, adapting some of the languages for people with lower health literacy, including more information about where testing can be done, including more male characters and actors from different ethnic groups, and improving the sound quality in certain parts.

Discussion

The culturally targeted video was informed by health behavior conceptual models, evidence-based risk communication strategies, and extensive formative research. Findings from the pilot with Latino community health workers showed a very high acceptability of the video in terms of overall satisfaction, as well as other specific aspects of the video (e.g., clarity of the information, potential usefulness with the Latino community in the USA). These findings are promising given that community health workers connect underserved populations with health services and could play a key role in the dissemination of the video if it is proven to be efficacious.

Few HBOC education interventions have been developed targeting at-risk Latinas (Joseph et al. 2010; Sussner et al. 2010; Vadaparampil et al. 2018). Prior interventions include a culturally targeted booklet (Vadaparampil et al. 2018), a culturally targeted DVD presentation (Sussner et al. 2010), and a computer presentation targeted to ethnically diverse populations with low health literacy, available in Spanish, but not culturally adapted (Joseph et al.

2010). Our intervention can complement and expand prior efforts. The video format can overcome health literacy barriers, especially in the Latino population that has a lower literacy level compared with other ethnic groups (Kutner et al. 2006). Importantly, the video is a cost-effective strategy that can easily be disseminated through the Internet (e.g., Facebook, YouTube) as suggested by the Latino community health workers in our study. Moreover, the widespread use of video and media on mobile devices offers a contemporary alternative to deliver health messages. These strategies may be especially beneficial for underserved populations, by facilitating access to health information (Anderson and Rainie 2015; Whittaker et al. 2012). Future studies should examine different implementation settings and dissemination options.

Opportunities, challenges, and lessons learned

Developing, refining, and producing a high-quality video to increase uptake of GCRA among at-risk Latinas was an enriching and collaborative process that benefited from the diverse perspectives of film artists and researchers. Multidisciplinary collaboration between scientists and filmmakers can provide models for innovative strategies to better reach and engage underserved populations. Few research studies connect scientific experts and artists (Baezconde-Garbanati et al. 2014; Wilkin et al. 2007). Lessons learned from our work contribute specific strategies for future efforts that intend to use video to improve health behaviors in underserved or hard-to-reach patient populations.

Discipline-specific differences and challenges We encountered some discipline-specific aspects and some challenges. *Timeline:* Research projects can take months or years. In this study, the formative phase (data collection and analysis) lasted 19 months. In contrast, the production team was accustomed to shorter time frames for projects (weeks). Changes in the timeline that affected filming dates (e.g., scheduling the focus group) can be extremely challenging for filmmakers, as it may imply the need to recast the actors. In the future, collaborations between researchers and artists would benefit from brief presentations at the onset of the project to educate each other about the respective fields and plan accordingly for potential challenges (e.g., timelines).

Balancing scientific precision and entertainment One of the common challenges of entertainment education is finding the right balance between scientific accuracy and entertainment (Green 2006). This applies not only to the scriptwriting phase, but also to the production and post-production phases. In filmmaking, it is common for actors to paraphrase lines and improvise to make speech more natural. However, for scientific videos, actors should follow the script verbatim. For instance, in our video, the phrase “there is a gene that causes cancer” could not substitute “there is a gene that increases the risk of cancer”. The actors had difficulty memorizing the exact lines, including medical or scientific nuances of the script. Consequently, the producers had to film more takes than usual. The need for retakes presented a challenge as the project was constrained by limited time and budget.

In movie-making, the product typically changes at each step of the process from the writer, to the videographer, to the editor. However, this project required fidelity to the health information included in the final script. To check for scientific accuracy, the NCDA worked in close collaboration with the research team during the edition process. The length of the video had to be limited for optimal dissemination. Thus, the production team had to cut scenes and used minimal “B-roll,” or transition shots, to cut down on time. Rather than story-driven dialog, the writing was driven mainly by the scientific messages that had to be delivered. Therefore, the scriptwriter had to be creative in conveying all the health information while devoting enough time for character development. Having an initial meeting between researchers, film artists, and production team is recommended to discuss the differences between entertainment education and entertainment video.

Study strengths and limitations

The sample for the formative research was a convenience sample of first-generation at-risk Latina immigrant women (mostly from Central and South America) from the Washington DC metropolitan area. Thus, the script may not

resonate with the experiences of at-risk Latina women living in rural areas, from different geographic areas (e.g., the Caribbean), or from second generations. Despite the limitations, this study has several strengths. This video is one of the few culturally targeted interventions developed (Joseph et al. 2010; Sussner et al. 2010; Vadaparampil et al. 2018) to improve psychosocial outcomes and increase GCRA uptake for at-risk Latina women. Additionally, the use of conceptual models, evidence-based risk communication strategies, and extensive formative research using a mental models approach to inform the development of the script is a significant strength of this study. The interdisciplinary collaboration between scientists and artists constitutes a promising avenue to enhance translational efforts and reduce disparities.

Practice implications

This study has implications for different types of providers who work with at-risk Latina populations. Given the dearth of education materials in Spanish about HBOC and GCRA, this video could be a tool for navigators and community health workers to increase awareness and knowledge about HBOC and GCRA in the community. Due to the scarcity of Spanish-speaking counselors (Augusto et al. 2018) and the documented challenges when interpreters are used (Hurtado-de-Mendoza et al. 2018; Joseph and Guerra 2015; Joseph et al. 2017), future studies could explore whether viewing the video prior to counseling may increase at-risk Latina women engagement in genetic counseling sessions.

Research recommendations

We are currently conducting a single-arm trial with at-risk Latinas to pilot an intervention that includes watching the video plus navigation to assess uptake of genetic counseling as well as other psychosocial outcomes. Future studies should test the efficacy of this video in an RCT and explore the potential for dissemination and implementation in different settings. Future studies should also examine the efficacy and cost of different video modalities (e.g., using animation vs. real actors) and mediums (e.g., print fotonovela vs. audiovisual) for different target audiences (e.g., age groups, cultures).

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

Informed consent Was obtained from all individual participants included in the study.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

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