Exploring attitudes, beliefs, and communication preferences of Latino community members regarding *BRCA1/2* mutation testing and preventive strategies

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Purpose: To inform development of a culturally sensitive hereditary breast and ovarian cancer communication initiative and related clinical genetic services. **Methods:** Five focus groups were conducted with 51 female and male Latinos. Educational materials were designed to communicate information about hereditary breast or ovarian cancer and availability of relevant clinical services or prevention strategies. Focus groups explored participants' knowledge, attitudes, and beliefs about hereditary breast and ovarian cancer, *BRCA1/2* testing, and communication preferences for hereditary breast and ovarian cancer health messages. **Results:** Overall, awareness of familial breast and ovarian cancer and availability of genetic risk assessment was low. Once informed, participants held favorable attitudes toward risk assessment and counseling services. Critical themes of the research highlighted the need to provide bilingual media products and use of a variety of strategies to increase awareness about hereditary cancer risk and availability of clinical genetic services. Important barriers were identified regarding family cancer history communication and cancer prevention services. Strategies were suggested for communicating cancer genetic information to increase awareness and overcome these barriers; these included both targeted and tailored approaches. **Conclusion:** This research suggests that cancer genetic communication efforts should consider community and cultural perspectives as well as health care access issues before widespread implementation. ***Genet Med* 2010:12(2):105–115.**

Key Words: *genetic testing, hereditary breast and ovarian cancer, Latino perspectives, focus groups, communication*

An estimated 5–10% of breast and ovarian cancers are attributed to deleterious *BRCA1/2* mutations, which account for ~20–40% of familial breast cancer and for the majority of familial ovarian cancers. The strength of the associations varies with the family history.[1,2] Estimated average lifetime cumulative risks in *BRCA1/2* carriers are 49–82% for breast cancer and 18–54% for ovarian cancer.[3,4] A growing body of evidence demonstrates the benefits of providing surveillance, chemoprevention, and risk-reducing surgical options to carriers of *BRCA1/2* mutations.[5–7]

The United States Preventive Services Task Force and the National Comprehensive Cancer Network have determined that women at high risk would benefit from genetic counseling that helps patients or family members make informed decisions about genetic testing and that enhances selection of early cancer detection or risk-reduction strategies.[7,8] However, health systems in the United States face challenges in providing culturally relevant cancer genetic services to an increasingly diverse population. Despite the growing availability of genetic counseling and testing for hereditary breast cancer, awareness and use of these services is low, particularly in Latinos and other minority groups.[9,10] Awareness of hereditary cancer risk and genetic testing for cancer susceptibility can enhance informed decision making about whether to seek such services.[11] However, awareness of these and other health concepts varies by sociodemographic characteristics, family history, acculturation factors, and elements that influence access to information through the health care system or other communication channels (e.g., mass media, social networks).[10,12–14] An individual's decision regarding whether or not to seek clinical cancer genetic services may also be influenced by knowledge, cognitions, emotions, family communication, and sociodemographic and clinical characteristics.[15–17] To enhance informed decision making about cancer genetic counseling or testing among members of diverse populations, it has become increasingly important to gain a better understanding of cultural, access, and psychosocial issues related to factors influencing the use of these health services and communication of genetic information.

Latinos are the largest minority group in the United States and the fastest growing segment of the population. The Latino population in the United States currently consists of >37 million people and is expected to comprise 25% of the US population by the year 2050. Latinos are an ethnically and racially diverse population, with origins in Central and South America, the Caribbean, and Spain.[18]

Breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death in Latina women (Latinas). Although the incidence of breast cancer is lower in Latinas than in non-Latina whites, Latinas are more likely to be diagnosed with the disease at younger ages and later stages.[19] Traditionally, Latinas have been less likely than women of other ethnic or racial backgrounds to use preventive services such as mammograms and clinical breast examinations.[20] Furthermore, Latinos are much more likely than non-Latino whites to be uninsured. Nearly one-third of Latinos have no health insurance, limiting their access to cancer screening and quality medical care.[21]

As the US population diversifies, it is imperative that all segments of the population be educated about hereditary cancer risk, the availability of genetic counseling and testing services, and cancer prevention strategies to facilitate informed decisions about these matters. Furthermore, as these services are more broadly disseminated into mainstream clinical practice, it is important to understand factors that contribute to lower levels of awareness and utilization of cancer genetic services. Such factors can be targeted to increase awareness and promote in-

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formed decision making regarding preventive care. For this information to effectively reach ethnic subgroups such as Latinos, it must be relevant and meaningful to them, capturing their attention and addressing their questions and concerns.

Although most published data indicate similar proportions of cancers attributable to hereditary cancer predisposition genes among different ethnic groups,[22–24] information on Latinos' attitudes toward *BRCA1/2*-related health services and communication preferences is scarce. Available data suggest that awareness of genetic testing for cancer risk is lower among Latinos than among non-Latino whites[10]; this implies disparities in the use of cancer genetic services. Most research on inherited breast cancer susceptibility and genetic testing for such susceptibility has focused on non-Latino whites and a growing body of research focuses on African Americans.[9] To ensure effective translation of genetic discoveries into clinical and public health settings, more information is needed regarding attitudes toward and use of *BRCA1/2* genetic counseling or testing and relevant preventive strategies in ethnic subgroups such as Latinos.[25]

Cancer genetic educational strategies and health services that have been developed for implementation with non-Latino whites may be inappropriate and ineffective for Latinos.[26] Cultural and language barriers may influence the use of such services by Latinos.[14] By identifying important health perceptions and issues for enhancing Latino community awareness about hereditary breast and ovarian cancer, as well as understanding and targeting unique facilitators and barriers to use of cancer genetics and related preventive services, awareness and use of these services could improve. According to the basic principles of social marketing, the development of appropriate and effective health communications and services must be based on an in-depth understanding of the target population's attitudes, perceptions, informational needs, and communication preferences.[27] However, as previously mentioned, such data on Latinos are sparse. To address this gap and assess hereditary breast and ovarian cancer-related communication strategies, we conducted a series of focus groups with members of the Latino community. The purpose of this article is to describe the findings of the qualitative research that was conducted via these focus group discussions. Latino leaders and lay community members were asked questions related to factors that might influence awareness, attitudes, and beliefs about hereditary breast and ovarian cancer and use of *BRCA1/2* counseling or testing and relevant preventive strategies. We also identified communication preferences regarding genetic education and counseling.

MATERIALS AND METHODS

Study design

The focus groups were structured using guidelines established by Morgan and Krueger.[28] Focus groups can be a useful means of preliminary data collection when little is known about the phenomenon of interest in general or among a particular segment of the population.[29] Focus groups generate information through interactions between participants; concepts can be revealed in such a way that no single participant could have fully articulated alone.[30] Qualitative efforts that elicit salient attitudes, beliefs, and additional issues about a particular health problem represent an important step toward developing culturally relevant health education programs and clinical services.

A community-based sample of Latinos was used to gather information about knowledge gaps, attitudes, and beliefs that may contribute to underuse of cancer genetics services. Latino community leaders were also recruited as key informants because they often can provide informed opinions about the research query by virtue of their knowledge of and access to the Latino community, and they can help in planning for delivery of health interventions. Snowball and convenience sampling methods were used to recruit individuals to the groups.[31] Focus groups were conducted by a professional bilingual facilitator. Separate sets of focus groups were conducted with Latino community members and community leaders. During a 1-week period in February 2003, three focus groups of Latino community members were conducted, including two groups with women and one group with men. Subsequently, two focus groups were held over a 1-week period in July 2003; participants were prominent leaders in the Latino community. Male and female community leaders participated in separate focus groups. The goal of the focus groups was to collect information about cancer genetics-related knowledge, attitudes, beliefs, and barriers or facilitators to use of cancer genetic services. In addition, focus groups assessed preferences regarding communication of cancer genetic and preventive health messages.

The research protocol was reviewed and approved by the University of Utah Institutional Review Board. All participants reviewed and signed informed consent forms and completed a brief demographic survey. Light refreshments were provided at the focus groups. Organizations that provided a community leader participant were given a $50.00 cash donation, and the other community participants were provided with a $30.00 gift certificate to a local grocery store chain as a token of appreciation for their participation.

Participants and setting

We purposely selected participants to achieve variation in gender, educational level, and community role. Both men and women were solicited because both sexes are at increased risk for cancers associated with *BRCA1/2* mutations, may be influential in relevant health care decisions, or provide social support to affected or at-risk family members or significant others. Our experience suggested that educational level impacts the effectiveness of cancer risk communications and health behaviors. Thus, we wanted to have variation in educational level for the lay participants. Furthermore, we believed that inclusion of community leaders was important because they often provide social support and anticipatory guidance regarding health care decisions, link community members with health care providers, and assist with and influence dissemination of health information. Participants were recruited through local Latino community organizations, fliers, radio advertisements, and through the personal and professional contacts of the Latino Community Alliance based in Salt Lake City. Fifty-one men and women participated in one of the five focus groups. General eligibility requirements for participation included identifying oneself as Hispanic or Latino, being at least 18 years of age, and having the mental and physical ability to understand and sign the informed consent document and to participate in a focus group. Each of the five focus groups also had specific eligibility requirements: (1) women with a high-school education or less ($n = 11$), (2) women with some secondary education ($n = 11$), (3) men with any educational background ($n = 14$), (4) men with leadership positions in local community organizations ($n = 8$), and (5) women with leadership positions in local community organizations ($n = 7$). Participants in the latter two groups worked in government leadership positions, for-profit organizations, or nonprofit community groups.

Data collection

An experienced, trained, bilingual Latina facilitator with expertise in cancer control, cancer genetics, and public health practice moderated the focus group interviews. She guided participants through a predetermined outline of questions, presentations of health messages related to hereditary breast and ovarian cancer, and discussion topics. Table 1 provides a summary of sample topics and questions. The objectives of the study guided the development of a moderator's guide with open-ended questions and specific probes. A bilingual notetaker was also present. A PowerPoint slide presentation was given to participants after asking them questions about their beliefs, attitudes, and knowledge about cancer in general, and hereditary breast and ovarian cancer, in particular. The moderator used the slide show to present information about hereditary breast and ovarian cancer, clinical genetic services, and preventive options. Health messages and graphics used in our familial cancer clinic and a previous *BRCA1* testing study in African Americans were translated into Spanish; pictures of Latinos were substituted for pictures of non-Latinos.[32] The presentation included (1) basic information on hereditary breast and ovarian cancer (e.g., risk factors, incidence, and penetrance estimates); (2) concepts related to autosomal dominant transmission; (3) the process of genetic risk assessment including *BRCA1/2* testing; (4) risks, benefits, and limitations of *BRCA1/2* testing; and (5) psychosocial and cultural issues. Participants were asked to view and respond to the content and related visual aids for each of these health messages during the group discussions.

All focus groups were conducted in Salt Lake City at a Latino community center, Centro de la Familia de Utah. Each focus group lasted between 1.5 and 2 hours. Focus groups were stratified by gender in the event that men and women would respond differently. The three focus groups of members of the Latino community were conducted entirely in Spanish, whereas those comprised of Latino community leaders were conducted in both Spanish and English.

Data analysis

Each of the focus groups was audiotaped. Transcripts of focus groups conducted in Spanish were translated from Spanish to English and transcribed verbatim by a bilingual transcriptionist. The transcripts were reviewed for accuracy, and corrected as needed, by a bilingual study coordinator. Qualitative data transcribed from the focus group sessions were manually coded; statements were sorted, categorized, and arranged into themes. We used a phenomenological approach, striving to both understand participants' experiences and avoid imposing external views.[29] Data were collected and analyzed using a collaborative approach, with summarizing, debriefing, and consensus building at each step. Thematic text identification was informed by literature reviews, investigators' a priori understandings, the moderators' guide, and qualitative text. When necessary, themes were modified or further broken down into subthemes. In addition, thematic analysis was used to evaluate transcribed data.[29] Thematic analysis of the participant responses focused on the general agreement among participants in each group, consistency of findings across groups, and concordance among the assessments of three author coders (A.K., S.S., and M.A.-L.). Two authors (A.K. and S.S.) conducted detailed reviews of the transcripts for responses related to key study themes, for consistency of responses among participants and across groups, and for levels of agreement. Each comment then was categorized using these general themes, and subthemes were identified given our interest in the overall attitudes and perceptions of the focus group participants. The findings were derived from the analysis of all focus groups collectively, although subthemes that were prevalent in the majority of focus groups were identified. After the team members' discussion and analysis of issues, concerns, and ideas that emerged during the focus groups, two authors (A.K. and S.S.) organized findings into five broad themes and identified exemplar quotes.

RESULTS

Participant characteristics

Table 2 presents demographic information about focus group participants. Participants' age ranged from 19 to 74 years, with a mean age of 42 years. All participants identified themselves as first (92%) or second (8%) generation Hispanic or Latino. The majority of participants were women (57%). Eight percent of participants had a personal history of cancer and 76% reported having one or more relatives with cancer; 20% had a first- or second-degree relative with breast and/or ovarian cancer. Participants had resided on the US mainland for an average of 14 years, with a range of 4 months to 73 years. Ninety percent of participants reported Spanish as their first language ($n = 46$), 90% of participants were born in Central or South America ($n = 46$), and all participants' ancestors were from Central America, South America, or Spain.

Qualitative findings

The results are organized into five broad themes: (1) attitudes and beliefs about cancer; (2) awareness of and attitudes about hereditary breast and ovarian cancer and genetic testing; (3) preferences regarding medical management of hereditary breast and ovarian cancer; (4) barriers to cancer prevention and control; and (5) communication issues and preferences.

For each theme and category, we provide illustrative examples from the focus group transcripts in Table 3. Quotes provided are verbatim.

Attitudes and beliefs about cancer

Participants articulated a range of issues regarding cancer. The following words were used by participants to describe their thoughts when hearing the word cancer: pain, suffering, sadness, death, worry, fear, anger, and agony. Overall, participants had fatalistic views about cancer and expressed concerns about the financial impact of cancer diagnosis. Participants discussed commonly held beliefs that being told one has cancer is similar to being told that death would be imminent, and there is really nothing that one can do about it. Concerns about treatment-associated expenses were related to the fear of not being able to cover medical or financial obligations or of imposing an economic burden on the family.

Additional issues discussed included cultural taboos surrounding cancer, views of cancer as contagious, and secrecy and shame associated with a cancer diagnosis. Responses indicated that many members of the Latino community and of the participants' families did not want others, even their own family or friends, to know they have cancer; such sentiments are common in their countries of origin. Participants discussed how this cultural taboo about revealing a cancer diagnosis creates stigma and an attitude of secrecy and shame. Considerable discussion centered on how the stigma, shame, and secrecy associated with cancer could be a barrier to cancer genetic and relevant prevention services because many Latinos may not be aware of their family cancer history and hereditary risk. The importance of

Table 1 Focus group moderator guide topics and questions

Topic	Questions
Cancer beliefs and attitudes	What comes to your mind when I mention the word cancer?
	What do you think it means to your friends and relatives?
	What do you think causes breast cancer?
	What do you think causes ovarian cancer?
	If you had cancer who would you tell? Who wouldn't you tell?
	If one of your close relatives had cancer, do you think that they would tell you?
Knowledge about breast and ovarian cancer genetics and *BRCA1/2* testing	What do you know about cancer that runs in families?
	Have you ever heard that breast and/or ovarian cancer can be inherited?
	Have you heard about genetic testing for inherited or familial breast and ovarian cancer?
	What do you know about this type of genetic testing?
	Among Latinos, who is more likely to know about this test? . . . . not know about this test?
Presentation of communication messages about hereditary breast and ovarian cancer and *BRCA1/2* testing	What did you think about the presentation (content and visual aids)?
	What do you think needs to be changed?
	What needs to be added, or deleted?
Attitudes and concerns about *BRCA1/2* testing	Given what you now know about genetic testing for hereditary breast and ovarian cancer, what are some of your concerns about the *BRCA1/2* test?
	What do you think are the advantages of *BRCA1/2* testing?
	What do you think some of the disadvantages of *BRCA1/2* testing are?
	Do you think that age, gender, socioeconomic status, legal status could affect one's decision about getting tested?
Access issues	Who do you think is most likely to get a test for hereditary breast and ovarian cancer?
	Who is least likely to get it?
	Think about the typical Latino in the Colorado, New Mexico, and Utah area, what barriers might they encounter in getting a test?
	Can you think of any barriers that might prevent getting genetic education and counseling and *BRCA1/2* testing? Cancer screening? Risk-reducing surgery?
	What might prevent or be barriers to having prophylactic surgery of the breasts among *BRCA1/2* mutation carriers? Prophylactic surgery of the ovaries?
	What would motivate someone to get a *BRCA1/2* test?
Interpersonal communication	If you were considering getting a *BRCA* test, who would you talk for advice for getting the test?
	How are health issues communicated in your family?
	Do you think that the health information in your family is accurate? Tell me more about this.
	Would you talk to a health care provider if you wanted more information about getting a *BRCA* test? Who would this person be?
	If you got a *BRCA1/2* test who would you tell? Reasons?
	Who wouldn't you tell? Reasons?
	How would you prefer that your family members received the results?
Informational preferences	How would you go about getting information about *BRCA1/2* testing?
	Who would you turn to for advice about having a *BRCA1/2* test?
	If you were considering getting *BRCA1/2* testing, how would you like to receive the information?
	What would be the best way to get information about hereditary breast and ovarian cancer and *BRCA1/2* testing to Latinos who have a family history of cancer and may be at increased risk for cancer?

Table 2 Focus group characteristics

Subgroup	Less educated females, $N = 11$ (%)	More educated females, $N = 11$ (%)	Male, $N = 14$ (%)	Female community leaders, $N = 7$ (%)	Male community leaders, $N = 8$ (%)	Total, $N = 51$ (%)
Employment status						
Full time	5 (46)	5 (46)	7 (54)	6 (86)	7 (87)	30 (60)
Part time	2 (18)	2 (18)	2 (15)	1 (14)	1 (13)	8 (16)
Not employed	4 (36)	4 (36)	4 (31)	0 (0)	0 (0)	12 (24)
Martial status						
Married	8 (73)	9 (75)	12 (80)	5 (71)	7 (100)	41 (80)
Not married	3 (27)	3 (25)	2 (20)	2 (29)	0 (0)	10 (20)
Personal cancer history						
No	9 (82)	10 (90)	14 (100)	6 (86)	8 (100)	47 (92)
Yes	2 (18)	1 (10)	0 (0)	1 (14)	0 (0)	4 (8)
Relatives with any type of cancer						
None	0 (0)	0 (0)	5 (36)	2 (29)	5 (63)	12 (24)
1 or more	11 (100)	11 (100)	9 (64)	5 (71)	3 (37)	39 (76)
Relatives with breast or ovarian cancer						
None	9 (82)	7 (64)	13 (93)	5 (71)	7 (87)	41 (80)
1 or more first or second degree relatives	2 (18)	4 (36)	1 (7)	2 (29)	1 (13)	10 (20)

knowing one's family history of cancer was recognized and emphasized as an important public health intervention target.

Awareness of and attitudes about hereditary breast and ovarian cancer and genetic testing

None of the participants in the community member focus groups had ever heard of genetic testing for *BRCA1/2*; only two female and two male community leaders reported having previous knowledge of *BRCA1/2* testing. All focus group participants, with the exception of one woman, expressed favorable attitudes toward *BRCA1/2* genetic testing. Perceived benefits of genetic testing included knowledge, more frequent screening, early treatment, and information for children and future generations. Perceived limitations of genetic testing included cost and potential adverse psychological sequelae (i.e., anxiety and fear). Participants felt that the cost of the genetic test and associated provider and clinic costs would serve as a major deterrent for accessing cancer genetic services because many Latinos have low incomes and no health insurance.

Preferences regarding medical management for hereditary breast and ovarian cancer

Responses indicated a strong preference for screening rather than prophylactic surgery. In general, both male and female participants were strongly opposed to prophylactic mastectomy but were more receptive to prophylactic oophorectomy for those who are at risk for or who have hereditary breast and ovarian cancer. Virtually all female participants agreed that they would not choose to have their breasts removed as a cancer risk-reduction strategy, and many stated that they would not have their ovaries removed to reduce their cancer risk. However, some women felt that this decision would vary based on their age. Concerns that prophylactic surgery, especially risk-reducing mastectomy, would affect women's body image and sexuality were expressed. Generally, men were opposed to prophylactic mastectomy but were more supportive of mastectomy as cancer treatment.

Barriers to early detection and risk-reduction services

Participants discussed a number of barriers to general prevention services, as well as barriers specific to hereditary breast and ovarian cancer. Prevalent barriers were related to financial access (i.e., cost and lack of insurance), discrimination, embarrassment and modesty, fear, lack of awareness about the preventive strategy, perceived lack of need for screening or testing in the absence of symptoms, and specific issues such as age for starting screening and frequency of testing. Additional barriers included secrecy related to either disclosing symptoms or to not wanting to be viewed by others as "flawed," procrastination, language barriers, fear about immigration status disclosure, fatalism, lack of interest, and lack of knowledge or information.

Cost was the barrier that participants in all focus groups mentioned most frequently. Many strongly agreed that both cost and lack of insurance are major barriers to obtain cancer screening among Latinos residing in the United States. Furthermore, many participants felt that Latinos' access to quality health care was restricted because of their language and economic limitations. Fatalistic attitudes about cancer and fear of knowing that

Table 3 Themes and representative quotes from focus group participants

Themes and categories	Exemplar quotes
Attitudes and beliefs about cancer	
Fatalism	"I think that . . . what scares me is . . . . when they say 'cancer' one thinks that she will die soon."
Fear	"Most people who immediately think about cancer are very often inundated with fear, because most of the information we have about cancer has been terminal . . ."
Stigma	"I didn't want you to know that we had a flaw in the family." (because of a family history of cancer)
Awareness of and attitudes about hereditary risk and BRCA genetic testing	
Cancer genetic attributions	"I guess the idea is that if somebody in your family had cancer . . . somebody's gonna get it . . . in your family."
Knowledge about genetic testing	"I think you carry [cancer] in your blood."
Benefits of genetic testing	". . . Getting treatment in time. Being better prepared . . . Getting a more frequent check-up."
Access barriers to genetic testing	"I wouldn't have [*BRCA* testing] done . . . I know that it would be very beneficial, but the bills . . . I would ignore it, it's extremely costly. It's beneficial to my daughters, and it is a benefit for my daughter's children, but currently the economic situation is not so flexible for me to have this exam done."
Fear of knowing	"Most of the people do not want to know if they have the cancer right now. Let alone, I think it will be harder for them to find out that they have a gene or a mutation that may cause . . . their body to develop cancer . . . in the future, and so I think for a lot of people just knowing that they have the mutation will be a lot more of anxiety source than actually helpful.. . . "
Preferences regarding medical management of hereditary breast and ovarian cancer	
Body image	"I would have the ovaries extracted, but the breasts, from what I saw, is more traumatic. Because it's physical. Before your eyes and the eyes of others. But the ovaries are internal and nobody sees them, so of course I would have them extracted."
Femininity	"Thank God I'm getting a divorce anyway, because then I'd have to get his permission and he wouldn't give it to me, because he would think I would be less of a woman."
Barriers associated with screening	
Financial access barriers	"I talk to women about doing . . . early detection screenings, and most of what they tell me is, 'I don't want to know, because I can't afford to pay for my treatment, because I have so many things going in my life I can't afford to be sick,' and so most of the people don't want to know that they have anything. . . "
Fear	"I think it's fear . . . just hearing the word cancer we become paralyzed. . . "
Embarrassment	". . . many people, out of embarrassment that the doctor will see them, they don't go in [for a check-up]."
Secrecy	"What I've noticed a lot is some [Hispanic] patients will not reveal everything that's wrong with them. They'll keep some of that back, and that doesn't help the doctor to help them . . ."
Procrastination	"I think that the problem that characterizes us as Hispanics is that we leave everything until the very last minute . . . and the consequences come from that . . . we wait until we feel the symptoms to go have the check-up for cancer prevention. So then we never really do it, nor will we, until we start feeling a little symptom."
Discrimination	"[Health care providers] get mad at us because we don't speak their language!"
Language	". . . the doctor asks, 'Do you have insurance?' 'No.' 'Well, then forget it, because it's too expensive.' They don't even tell you what it's about, because it's too expensive."
Socioeconomic status	
Communication issues and preferences	
Interpersonal communication	". . . It's been my experience that my parents and other parents were reluctant to discuss [cancer] with children . . . I know what my father died of, but not my grandparents, and I have no history. I have no accurate history."

(Continued)

Table 3 *Continued*

Themes and categories	Exemplar quotes
Channel of targeted communication preferences	"I've noticed that people that arrive here . . . the first thing we do is ask for a Catholic church. So then, that is where we expect to find a lot of information. And basically, it is there, in school and at church, where we are going to go [for information] because of our children and our families."
Source of cancer genetic information	". . . pardon my prejudice, but I don't want to see white health care providers talking to the Latino community in English on TV. . . . I want to see Latinos, because the connection is going to be stronger."

one has cancer were cited as barriers to screening. Fatalistic attitudes encompassed sentiments that cancer is God's will, and that cancer is synonymous with death. Fear about dying from cancer was raised as an important barrier to screening. All the women's groups also mentioned embarrassment, modesty, and secrecy. Participants discussed procrastination, not making screening a priority, and waiting to get screening until physical symptoms appear as additional barriers. With the exception of financial access barriers, participants felt that cognitive and social barriers could be modified through public health and clinical interventions.

Communication issues and preferences

The final theme that emerged was communication-related issues and preferences. An overarching theme across focus groups concerned how attitudes toward and beliefs about cancer may minimize communication with family members and care providers about familial cancer risk. These beliefs were previously mentioned and include secrecy, stigma, and fear. The general consensus among all groups was that interventions are needed to optimize communication of information such as family history of cancer and availability of genetic test results. Such potentially lifesaving information was viewed as critical in promoting health.

Overall, participants found the health messages and visual aids acceptable. They indicated that the visual aids were colorful, had pictures of Latino-appearing people, used large print, and used diagrams and pictures to display concepts. Preference was expressed for use of easy-to-interpret materials that use simple words and avoid unnecessarily technical information. Participants recommended clear definitions of technical concepts such as gene and mutation, and inclusion of a glossary that defines these and other technical terms. They also recommended that the information be highly relevant to the topic of hereditary breast and ovarian cancer, and that unnecessary information (e.g., detailed information about genetics) be omitted. Other than reduction of technical details unrelated specifically to hereditary breast and ovarian cancer or to an individual person, participants viewed the type and amount of information as appropriate.

In contrast with the views held by most participants, some individuals requested more detailed information in the health messages content and visual aids. Mixed opinions within the groups about the importance of detailed information on genetics and cancer risk indicate variations in the level of information desired. One suggested approach to addressing these differences was to use basic educational materials for the target population and to provide additional information when possible (e.g., individual counseling and direction toward computer programs that guide individuals through comprehensive explanations) for those who request it.

Participants provided suggestions about reaching Hispanic and Latino communities for clinical cancer services and notification about research opportunities. Participants suggested using Spanish language radio and television, community meetings or discussions, schools, hospitals, clinics, churches, fliers or pamphlets, public service announcements, the internet, and work places. Participants in two of the focus groups discussed using sensational news, "the kind of news that exaggerates everything, like . . . the car crashed and turned over and did several flip flops . . ." to reach a Hispanic or Latino audience. Schools and churches were emphasized in three of the groups. A male leader also suggested using clergy to reach the community, saying, ". . . in our community, health and religion are somewhat intertwined, having a Padre give out some information is probably a great way. I mean, they trust their religious leader anyways." Other suggestions included having prominent religious, political, and entertainment leaders endorse cancer prevention campaigns, and personally inviting community members to participate in research studies. A female leader explained the impact of using community members to reach the targeted community, saying, ". . . A real person who lives here among us . . . I know her and I hear her story, and all of a sudden it becomes real, you know." A different female leader agreed, saying, "Well, another thing you can add is testimonies . . . , cause it really does change when you hear it from someone who's been there." Participants were divided about whether non-Hispanic health care providers and researchers would be successful at reaching the Hispanic or Latino community. However, all participants agreed that the language barrier must be addressed by using bilingual health care providers and research staff.

DISCUSSION

The goal of this study was to assess beliefs and attitudes about hereditary cancer and genetic services. Our results illustrate a model of Hispanic and Latino community engagement in which researchers, clinicians, community leaders, and members of the target population work together to develop an effective and culturally relevant health education intervention.

Almost all participants had high levels of interest in genetic testing for inherited cancer susceptibility, despite the limited knowledge about genetics, that we and others have observed.[10,14] On learning about hereditary cancer and genetic risk assessments such as *BRCA1/2* testing, our focus group participants noted that genetic education opportunities could enhance health and reduce health disparities. These favorable attitudes are consistent with previous studies of Latinos[33] and other subgroups.[34]

Participants identified potential benefits of genetic testing for breast cancer susceptibility such as an increase in screening

frequency and early treatment, along with receiving knowledge that could enhance the health of children and future generations. These findings support a previous study that reported a feeling of duty to spread information about genetic cancer risk among family members of Latinas.[35]

Participants generally were satisfied with the visual aids used in this study. They emphasized the importance of reducing the level of technical detail and of presenting technical information clearly and succinctly. Some focus group members requested more information, whereas others desired less. These findings suggest that interventions are most effective when information needs are individualized. In addition, participants indicated that if personalized interventions are not feasible, the technical information provided should be adequate for all audiences. Those desired more detailed information could be directed to supplemental sources.

Previous studies have reported differences related to ethnic and/or racial background in the cognitive processing of risk information.[36] Such differences along with patients' literacy and numeracy levels can substantially impact the efficacy of genetic counseling.[36–38] Eichmeyer et al.[39] have shown that Latinos exhibit lower comprehension of numerical presentations of risk when compared with non-Latino whites; this finding suggests that qualitative representations could improve effectiveness. Graphical presentation of risk probabilities often increases understanding.[40,41] Culturally sensitive genetic counseling accounting for literacy issues[42] and translating risk-related knowledge into personally relevant information also can enhance the effectiveness of risk communication.[41]

Kreuter et al.[43] suggest entertainment education as an especially effective option for communication. Entertainment education narratives rely on cultural content and can take many forms including audio, visual, print, and mixed media.[43] For example, *telenovelas* are video narratives that might prove especially effective thanks to their ubiquity in the Latino community. Initial reports suggest that *telenovelas* increase breast cancer knowledge and positively influence attitudes toward screening among viewers.[44] Expanding the use of *telenovelas* to promote cancer genetics awareness would align with our focus group recommendations about providing educational messages from entertainers on Spanish language television programs.

Participants suggested many options that they felt could be used for effective communication of information about hereditary cancer, genetic testing, and risk-reduction strategies. They encouraged direct dissemination of information through discussion in schools and churches, information delivery using sensational or exciting language to capture attention, personal testimonials by influential Latino community members, and use of both Spanish and English. The efficacy of several of these suggested communication strategies has been documented.[45–49] However, our participants exhibited variable preferences and lacked consensus regarding the most appropriate communication channel.

Other studies have highlighted the importance of educating physicians or health care providers about the availability of cancer genetic services in areas with diverse populations.[25] If care providers are aware of the potential impact of these services, they are more likely to communicate relevant information with their patients and initiating referrals for risk assessment when appropriate. However, members of our focus groups highlighted a number of barriers to communication with care providers such as secrecy, embarrassment, fear, and experiences of discrimination. The use of culturally sensitive health communication strategies has proven effective in imparting knowledge and increasing desirable behaviors.

Focus group members perceived a variety of barriers to pursue appropriate health care. They described inequitable distribution of access to genetic information and relevant prevention services because of several factors, including psychosocial and cultural issues, inadequate access to pertinent information, and limited exposure to new knowledge and/or available technologies. Our findings agree with observational studies demonstrating that consequences of being uninformed contribute to racial and ethnic health disparities, particularly to disparities in cancer treatment and prevention.[20,50]

Participants also expressed concerns that other types of communication barriers, specifically those within families and between other social network members, may limit knowledge about one's family history of cancer. Cultural taboos surrounding cancer lead to secrecy, and thereby to nontransmission of family cancer history. When coupled with stigma and shame, such taboos may contribute to substantial knowledge deficits. It is interesting that ten men but only two women in our focus groups reported having no family history of cancer. Because recruitment was nonrandom and the subject of the focus groups centered on hereditary breast and ovarian cancer, this finding may be related to ascertainment bias or participant's interest that led more women than men with family histories of cancer to participate. Coupled with the already identified barriers to Latino family cancer history transmission, it may be that Latino men are even less aware than Latina women of their family cancer histories. This could result in children being less aware of their paternal than their maternal family history of cancer. This trend has been reported in other populations.[51,52] Further research is needed to determine whether this tendency is exacerbated in the Latino community because of cultural factors such as those encountered in our study.

Information is scarce regarding ethnic disparities in intrafamilial communication of family cancer history and genetic test results within the Latino community. One study examining cancer history reporting accuracy by probands with cancer in 1111 families showed a nonsignificant trend toward more accurate family history reporting by non-whites.[53] However, Hispanic probands only accounted for 4.7% of the subjects. Given the barriers to family cancer history communication that our participants reported, more research is needed to examine the impact of these barriers in a larger Latino sample. Although the US Surgeon General has implemented a campaign to increase family health history documentation among all Americans, optimal methods for accurately ascertaining family histories of cancer and other diseases have yet to be determined.[54] Because of the importance of family history in accurately assessing hereditary cancer risk,[55] we must develop and test strategies for overcoming barriers in this important area.

Effective communication of genetic information within families can impact familial health outcomes. Available data indicate that communication of cancer genetic risk within families can influence decision making about genetic testing, screening, and primary prevention.[56,57] A recent survey of Latina and non-Latina white women who were referred for hereditary breast or ovarian cancer risk assessment found that most women, regardless of ethnicity, indicated that their relatives should be informed about their genetic risk.[35] The majority also felt that the woman herself should disseminate this risk information to her family in person. However, more Latinas than non-Latina whites indicated a preference for the health care provider to directly provide the risk information to family members. These data indicate that once women are informed about the presence of a familial cancer risk, most desire to share this information with at-risk relatives. As was the case with our

focus group participants, many Latinos are unaware of genetic cancer risks,[39] and thus may be unaware of the importance of sharing family cancer information to help relatives understand their risks. Despite the barriers to family communication cited by our focus group participants, the findings from the study of MacDonald et al.[35] convey optimism that once individuals are educated about hereditary cancer risks, barriers to family cancer history dissemination may be overcome.

In addition to identifying the need to enhance education, overcoming practical aspects of achieving access to appropriate cancer genetic services and prevention services were commonly cited concerns across focus groups. Participants identified barriers including financial and linguistic issues, lack of knowledge about how and where to access services, and difficulties related to motivation (including fatalistic views about cancer, embarrassment or modesty, and waiting for symptoms to appear before seeking screening). Demographic research has shown that economically underprivileged Latinos experience high rates of unemployment and poverty,[20] factors that are likely to impact use of cancer screening and genetic testing.[58] Furthermore, compared with other ethnic groups, a significant proportion of US Latinos lack health insurance[20]; this may play a significant role in low screening rates.[59] Reforms regarding affordability of care are among the top concerns of many US citizens and the current US government administration, particularly because the financial strain becomes even more pronounced during a recession.[60] While awaiting significant reforms, some programs have obtained grants to cover clinical cancer genetics services for indigent or underinsured individuals.[25] Such programs may help poor Latinos to overcome known cost barriers.

Behavioral studies also have determined that cultural beliefs may negatively impact access to health care and screening behavior among Latino and other ethnic groups.[27,61] Community health workers (CHWs) have helped overcome such cultural barriers to adequate health care,[62] in part, because they often come from the community they serve.[63] The effectiveness of CHWs has been documented in a variety of settings, including cancer-specific care among Latinos.[45] Our findings suggest that CHWs could ameliorate disparities in health care behavior and access, including the barriers cited in our groups. CHW skills would be enhanced by partnering with bilingual health care services and culturally informed providers.

The range of attitudes our participants expressed toward preventive measures is in accordance with previous research about *BRCA* mutation carriers in the United States. For example, participants in these prospective studies used prophylactic mastectomy at an appreciably lower rate than prophylactic oophorectomy.[64,65] Furthermore, the findings of our study confirm a strong preference for surveillance rather than prophylactic surgery. Participants expressed greater concern about values and attitudes regarding body image and femininity than about financial access issues. Nonetheless, participants did express substantial apprehension about financial access to cancer genetic and screening services. Future research should examine behavioral responses to genetic risk assessment, as well as factors influencing preference-specific early detection and risk-reduction decisions among Latinos.[66]

Cost and fatalism are barriers to genetic testing according to our focus groups. These findings confirm previous observations in various ethnic groups. For example, one study involving 28 African American women at high risk for *BRCA1/2* mutations showed higher mean levels of fatalism among participants who proceeded with genetic testing than in those who declined testing.[67] In this particular instance, the cost of genetic testing was covered by the study. Further research could examine the significance of fatalism in the context of health care in the Latino community. Participants' experiences with discrimination, which was based primarily on insurance and linguistic issues, could negatively impact uptake of genetic counseling and many other health care behaviors.

Strengths and limitations

By not selecting for a personal or family history of hereditary breast and ovarian cancer, we were able to elicit public opinions that could not have been obtained had selection criteria been limited to families at high risk. Because of our community-based recruitment and the varying levels of education among our focus group participants, it is likely that the study population was an adequate representation of urban and suburban Latino community members and leaders in the Rocky Mountain area.

The results reported in this article have a number of limitations and should be interpreted with caution. The findings are based on five focus groups in the Salt Lake City metropolitan area, a community that may not be fully representative of Latinos in other areas of the US nonprobability sampling methods were used and therefore may not adequately represent the target population's beliefs and perceptions. Other possible limitations are that themes and categories described here do not necessarily represent data saturation among the studied Latino subgroups, and that changes in attitudes of individual and community could occur because of a variety of sociocultural factors over the passage of time since our initial data collection. Furthermore, health messages were transmitted by using a PowerPoint presentation, during which participants listened to verbal explanations that were augmented by illustrations on a screen and by handouts. Before deployment of communication interventions, it will be important to systematically evaluate the educational materials, taking into account the channels of communication through which they will be delivered. Future studies should assess how these findings generalize to larger, more representative samples of Latino men and women.

Implications and conclusion

The successful translation of genetic discoveries from research institutions to clinical care settings will depend on understanding and influencing patient, health care system, and societal factors that contribute to the effective uptake of these discoveries. To our knowledge, this is among the first studies to use community engagement strategies to qualitatively examine the knowledge, beliefs, and attitudes of Latinos and Hispanics regarding hereditary breast and ovarian cancer and relevant health services. Many of our participants' attitudes are similar to those reported by other studies focused on cancer education and screening. Our Latino focus group members validated assumptions about the importance of including key sociocultural factors in the design and implementation of genetics education and related clinical interventions. Our review of the literature and clinical experience with Latinos identified several factors that are important to reach this goal. These included using role models from the community in educational materials and health messages, increasing the availability of materials in Spanish, dispelling myths and misconceptions about cancer, promoting family communication about cancer and knowledge of one's family health history, considering the importance of religious or spiritual factors, and making use of community-based approaches.[27,68]

Consistent with previous findings, participant responses indicate that information needs to be personally relevant to be cognitively processed.[41,69] Focus group participants indicated that they have too many other day-to-day priorities for overly

general information about cancer risk and prevention to merit an individual's attention. Specifically, family care giving needs as well as family obligations may lead Latinas to delay attending to their own health care, often avoiding visits to care providers for reasons other than feeling ill.[68,70] Some participants contended that cancer risk was not personally relevant until someone important to them was diagnosed with cancer. Such beliefs carry substantial implications for the creation and delivery of health care messages. The community participation approach of this study can be used to design health care messages and thereby increase their effectiveness for the intended audience.

The themes and participant recommendations identified in our focus groups have important implications for culturally meaningful health education, as well as public health and clinical practice, regarding hereditary cancer. Concepts and strategies that community members identify as particularly relevant or effective may produce substantial improvement in the effectiveness of outreach efforts and communication of cancer information. Many of our participants' suggestions have proven to be efficacious in other studies. Consistent with social marketing and theories, participants articulated ways to develop educational materials and messages that consider both superficial structure and deep structure cultural sensitivity.[71] Providing materials and messages in Spanish, preferably by a Latino and at popular venues, helps to enhance superficial structure sensitivity. Hispanic media such as newspapers and radio, churches, community gatherings, and schools have been used successfully to distribute information about cancer and cancer screening to Hispanics and Latinos.[72] Our findings suggest that in addition to informing macrolevel outreach efforts, community-specific beliefs and knowledge should be incorporated into cancer education efforts to address deep structure cultural sensitivity. Future educational efforts should explicitly address cultural factors believed to be related to the causes of cancer, perspectives of cancer as a disease inspiring stigma and guilt, and body image issues that may inhibit screening and preventive health care behaviors. Increasing availability of culturally sensitive genetic cancer risk information to Latinos may aid in lowering barriers to sharing cancer history information with family members and health care providers. Enhanced awareness of perceived access and financial barriers to cancer screening and genetics services may also allow health care providers to explore options for low-cost services to the underinsured or noninsured and to conduct discussions in a culturally sensitive manner. Study findings may also help guide hereditary breast and ovarian cancer education materials and media targeting Latinos. Our participants' views regarding detail level and presentation techniques suggest that whenever possible, educational tools and health messages are most effective when a range of communication formats is available for selection by the individual.

These insights gained from focus group discussions can help guide the design and development of appropriate interventions for use in both community- and clinic-based cancer programs. The types of strategies identified by our study have the potential to enhance relevance and impact in both educational and clinical settings.

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REFERENCES

1. Frank TS, Deffenbaugh AM, Reid JE, et al. Clinical characteristics of individuals with germline mutations in BRCA1 and BRCA2: analysis of 10,000 individuals. *J Clin Oncol* 2002;20:1480–1490.
2. Pal T, Permuth-Wey J, Betts JA, et al. BRCA1 and BRCA2 mutations account for a large proportion of ovarian carcinoma cases. *Cancer* 2005; 104:2807–2816.
3. Evans DG, Shenton A, Woodward E, Lalloo F, Howell A, Maher ER. Penetrance estimates for BRCA1 and BRCA2 based on genetic testing in a Clinical Cancer Genetics service setting: risks of breast/ovarian cancer quoted should reflect the cancer burden in the family. *BMC Cancer* 2008;8:155.
4. Chen S, Parmigiani G. Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol* 2007;25:1329–1333.
5. Schwartz GF, Hughes KS, Lynch HT, et al. Consensus Conference Committee. The International Consensus Conference Committee. Proceedings of the International Consensus Conference on breast cancer risk, genetics, & risk management. *Cancer* 2008;113:2627–2637.
6. Gronwald J, Tung N, Foulkes WD, et al. Tamoxifen and contralateral breast cancer in BRCA1 and BRCA2 carriers: an update. *Int J Cancer* 2006;118:2281–2284.
7. United States Preventive Services Task Force. Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. *Ann Intern Med* 2005;143:355–361.
8. National Comprehensive Cancer Network. Genetic familial hereditary risk assessment: breast and ovarian cancer V.I. Fort Washington, PA: National Comprehensive Cancer Network, 2008.
9. Halbert CH. Genetic counseling and testing for breast cancer risk in African Americans. *LDI Issue Brief* 2006;12:1–4.
10. Wideroff L, Vadaparampil ST, Breen N, Croyle RT, Freedman AN. Awareness of genetic testing for increased cancer risk in the year 2000 National Health Interview Survey. *Community Genet* 2003;6:147–156.
11. Schwartz MD, Peshkin BN, Tercyak KP, Taylor KL, Valdimarsdottir H. Decision making and decision support for hereditary breast-ovarian cancer susceptibility. *Health Psychol* 2005;24:S78–S84.
12. Meischke H, Bowen D, Kuniyuki A. Awareness of genetic testing for breast cancer risk among women with a family history of breast cancer: effect of women's information sources on their awareness. *Cancer Detect Prev* 2001; 25:319–327.
13. Benjamin-Garner R, Oakes JM, Meischke H, et al. Sociodemographic differences in exposure to health information. *Ethn Dis* 2002;12:124–134.
14. Vadaparampil ST, Wideroff L, Breen N, Trapido E. The impact of acculturation on awareness of genetic testing for increased cancer risk among Hispanics in the year 2000 National Health Interview Survey. *Cancer Epidemiol Biomarkers Prev* 2006;15:618–623.
15. Kinney AY, Simonsen SE, Baty BJ, et al. Acceptance of genetic testing for hereditary breast ovarian cancer among study enrollees from an African American kindred. *Am J Med Genet A* 2006;140:813–826.
16. Bottorff JL, Ratner PA, Balneaves LG, et al. Women's interest in genetic testing for breast cancer risk: the influence of sociodemographics and knowledge. *Cancer Epidemiol Biomarkers Prev* 2002;11:89–95.
17. Ropka ME, Wenzel J, Phillips EK, Siadaty M, Philbrick JT. Uptake rates for breast cancer genetic testing: a systematic review. *Cancer Epidemiol Biomarkers Prev* 2006;15:840–855.
18. U.S. Census Bureau. Resident population estimates of the United States by sex, race and Hispanic origin [serial online]. 2001. Available at: http://www census gov/population/estimates/nation/infile3-1 txt. Accessed July 1, 2009.
19. Howe HL, Wu X, Ries LA, et al. Annual report to the nation on the status of cancer, 1975–2003, featuring cancer among U.S. Hispanic/Latino populations. *Cancer* 2006;107:1711–1742.
20. Smedley BD, Stith AY, Nelson AR, editors. Unequal treatment: confronting racial and ethnic disparities in health care. Washington, DC: National Academic Press, 2002.
21. U.S. Census Bureau. Health insurance coverage: 2001. Washington, DC: US Census Bureau, 2004 [serial online].
22. Weitzel JN, Lagos V, Blazer KR, et al. Prevalence of BRCA mutations and founder effect in high-risk Hispanic families. *Cancer Epidemiol Biomarkers Prev* 2005;14:1666–1671.
23. Olopade OI, Fackenthal JD, Dunston G, Tainsky MA, Collins F, Whitfield-Broome C. Breast cancer genetics in African Americans. *Cancer* 2003;97: 236–245.
24. Hall MJ, Reid JE, Burbidge LA, et al. BRCA1 and BRCA2 mutations in women of different ethnicities undergoing testing for hereditary breast-ovarian cancer. *Cancer* 2009;115:2222–2233.
25. Ricker C, Lagos V, Feldman N, et al. If we build it. Will they come?—establishing a cancer genetics services clinic for an underserved predominantly Latina cohort. *J Genet Couns* 2006;15:505–514.
26. Penchaszadeh VB. Genetic counseling issues in Latinos. *Genet Test* 2001; 5:193–200.
27. Elder JP, Ayala GX, Parra-Medina D, Talavera GA. Health communication in the Latino community: issues and approaches. *Annu Rev Public Health* 2009;30:227–251.

28. Morgan DL, Krueger RA. The focus group kit. Thousand Oaks, CA: SAGE Publications, 1998.
29. Patton MQ. Qualitative research and evaluation methods, 3 ed. Thousand Oaks, CA: Sage Publications, 2002.
30. Billison JM. The Power of Focus Groups: focus on international development, Barrington, Rhode Island. Barrington, RI: Skywood Press, 2004.
31. Trochim WMK. The research methods knowledge base, 2nd ed. Cincinnati, OH: Atomic Dog, 2001.
32. Baty BJ, Kinney AY, Ellis SM. Developing culturally sensitive cancer genetics communication aids for African Americans. *Am J Med Genet A* 2003;118:146–155.
33. Singer E, Antonucci T, Van HJ. Racial and ethnic variations in knowledge and attitudes about genetic testing. *Genet Test* 2004;8:31–43.
34. Halbert CH, Kessler LJ, Mitchell E. Genetic testing for inherited breast cancer risk in African Americans. *Cancer Invest* 2005;23:285–295.
35. MacDonald DJ, Sarna L, Giger JN, Van SG, Bastani R, Weitzel JN. Comparison of Latina and non-Latina white women's beliefs about communicating genetic cancer risk to relatives. *J Health Commun* 2008;13:465–479.
36. Kendall J, Kendall C, Catts ZA, Radford C, Dasch K. Using adult learning theory concepts to address barriers to cancer genetic risk assessment in the African American community. *J Genet Couns* 2007;16:279–288.
37. Health literacy: a prescription to end confusion. Washington, DC: The National Academics Press, 2004.
38. Fagerlin A, Zikmund-Fisher BJ, Ubel PA, Jankovic A, Derry HA, Smith DM. Measuring numeracy without a math test: development of the Subjective Numeracy Scale. *Med Decis Making* 2007;27:672–680.
39. Eichmeyer JN, Northrup H, Assel MA, Goka TJ, Johnston DA, Williams AT. An assessment of risk understanding in Hispanic genetic counseling patients. *J Genet Couns* 2005;14:319–328.
40. Schapira MM, Nattinger AB, McHorney CA. Frequency or probability? A qualitative study of risk communication formats used in health care. *Med Decis Making* 2001;21:459–467.
41. Julian-Reynier C, Welkenhuysen M, Hagoel L, Decruyenaere M, Hopwood P. Risk communication strategies: state of the art and effectiveness in the context of cancer genetic services. *Eur J Hum Genet* 2003;11:725–736.
42. Thompson HS, Wahl E, Fatone A, Brown K, Kwate NO, Valdimarsdottir H. Enhancing the readability of materials describing genetic risk for breast cancer. *Cancer Control* 2004;11:245–253.
43. Kreuter MW, Green MC, Cappella JN, et al. Narrative communication in cancer prevention and control: a framework to guide research and application. *Ann Behav Med* 2007;33:221–235.
44. Wilkin HA, Valente TW, Murphy S, Cody MJ, Huang G, Beck V. Does entertainment-education work with Latinos in the United States? Identification and the effects of a telenovela breast cancer storyline. *J Health Commun* 2007;12:455–469.
45. Wasserman M, Bender D, Lee SY. Use of preventive maternal and child health services by Latina women: a review of published intervention studies. *Med Care Res Rev* 2007;64:4–45.
46. Austin LT, Ahmad F, McNally MJ, Stewart DE. Breast and cervical cancer screening in Hispanic women: a literature review using the health belief model. *Womens Health Issues* 2002;12:122–128.
47. Hether HJ, Huang GC, Beck V, Murphy ST, Valente TW. Entertainment-education in a media-saturated environment: examining the impact of single and multiple exposures to breast cancer storylines on two popular medical dramas. *J Health Commun* 2008;13:808–823.
48. Aitaoto N, Braun KL, Dang KL, So'a T. Cultural considerations in developing church-based programs to reduce cancer health disparities among Samoans. *Ethn Health* 2007;12:381–400.
49. Sauaia A, Min SJ, Lack D, et al. Church-based breast cancer screening education: impact of two approaches on Latinas enrolled in public and private health insurance plans. *Prev Chronic Dis* 2007;4:A99.
50. Vega WA, Rodriguez MA, Gruskin E. Health disparities in the Latino population. *Epidemiol Rev* 2009;31:99–112.
51. Quillin JM, Ramakrishnan V, Borzelleca J, Bodurtha J, Bowen D, Baer WD. Paternal relatives and family history of breast cancer. *Am J Prev Med* 2006;31:265–268.
52. Kupfer SS, McCaffrey S, Kim KE. Racial and gender disparities in hereditary colorectal cancer risk assessment: the role of family history. *J Cancer Educ* 2006;21:S32–S36.
53. Ziogas A, Anton-Culver H. Validation of family history data in cancer family registries. *Am J Prev Med* 2003;24:190–198.
54. United States Department of Health and Human Services. U.S. Surgeon General's Family Health History Initiative. Available at: http://www.hhs.gov/familyhistory/. Accessed November 27, 2009.
55. Cohn WF, Jones SM, Miesfeldt S. "Are you at risk for hereditary breast cancer?": development of a personal risk assessment tool for hereditary breast and ovarian cancer. *J Genet Couns* 2008;17:64–78.
56. Ersig AL, Williams JK, Hadley DW, Koehly LM. Communication, encouragement, and cancer screening in families with and without mutations for hereditary nonpolyposis colorectal cancer: a pilot study. *Genet Med* 2009;11:728–734.
57. Mellon S, Janisse J, Gold R, et al. Predictors of decision making in families at risk for inherited breast/ovarian cancer. *Health Psychol* 2009;28:38–47.
58. Kieran S, Loescher LJ, Lim KH. The role of financial factors in acceptance of clinical BRCA genetic testing. *Genet Test* 2007;11:101–110.
59. Wells KJ, Roetzheim RG. Health disparities in receipt of screening mammography in Latinas: a critical review of recent literature. *Cancer Control* 2007;14:369–379.
60. Mereopol NJ, Schraq D, Smith TJ. American Society of Clinical Oncology Guidance Statement: the cost of cancer care. *J Clin Oncol* 2009;27:3868–3874.
61. Gorin SS, Heck JE. Cancer screening among Latino subgroups in the United States. *Prev Med* 2005;40:515–526.
62. Dohan D, Schrag D. Using navigators to improve care of underserved patients. *Cancer* 2005;104:848–855.
63. Fernandez ME, Gonzales A, Tortolero-Luna G, et al. Effectiveness of Cultivando la Salud: a breast and cervical cancer screening promotion program for low-income Hispanic women. *Am J Public Health* 2009;99:936–943.
64. Wainberg S, Husted J. Utilization of screening and preventive surgery among unaffected carriers of a BRCA1 or BRCA2 gene mutation. *Cancer Epidemiol Biomarkers Prev* 2004;13:1989–1995.
65. Botkin JR, Smith KR, Croyle RT, et al. Genetic testing for a BRCA1 mutation: prophylactic surgery and screening behavior in women 2 years post testing. *Am J Med Genet A* 2003;118:201–209.
66. Miller SM, Roussi P, Daly MB, et al. Enhanced counseling for women undergoing BRCA1/2 testing: impact on subsequent decision making about risk reduction behaviors. *Health Educ Behav* 2005;32:654–667.
67. Hughes C, Fasaye GA, LaSalle VH, Finch C. Sociocultural influences on participation in genetic risk assessment and testing among African American women. *Patient Educ Couns* 2003;51:107–114.
68. Tejeda S, Thompson B, Coronado GD, Martin DP. Barriers and facilitators related to mammography use among lower educated Mexican women in the USA. *Soc Sci Med* 2009;68:832–839.
69. Kreuter MW, Lukwago SN, Bucholtz RD, Clark EM, Sanders-Thompson V. Achieving cultural appropriateness in health promotion programs: targeted and tailored approaches. *Health Educ Behav* 2003;30:133–146.
70. Weiler DM, Crist JD. Diabetes self-management in a Latino social environment. *Diabetes Educ* 2009;35:285–292.
71. Black DR, Blue CL, Coster DC. Using social marketing to develop and test tailored health messages. *Am J Health Behav* 2001;25:260–271.
72. Zavertnik JJ. Strategies for reaching poor Blacks and Hispanics in Dade County, Florida. *Cancer* 1993;72(3 suppl):1088–1092.