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ORIGINAL ARTICLE

To worry or not to worry: breast cancer genetic counseling communication with low-income Latina immigrants

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Abstract The purpose of this pilot study was to describe communication practices during hereditary breast cancer genetic counseling (GC) with low-income immigrant Latina patients in a public hospital setting. We utilized qualitative ethnographic methods, including direct observation of GC appointments with Latina patients at a public hospital offering free GC and *BRCA* testing and in-depth qualitative interviews with patients after they had received their *BRCA* genetic test results. Twenty-five patients participated; 20 were observed during genetic counseling appointments, and ten participated in interviews after *BRCA* testing with six participating in both observations and an interview. Analyses of qualitative data from observation field notes and interviews identified both strengths and limitations of current communication practices within the following themes: (1) family health history communication, (2) education regarding genes and genetics and patient information needs, (3) the purpose of the genetic test, (4) genetic test results and cancer risk, (5) building rapport and providing support, and (6) medical interpretation for monolingual Spanish speakers. As access to cancer GC expands in the public safety net settings and for the diverse populations they serve, it is critical to ensure effective communication in order for patients, whether or not they have a *BRCA* mutation, to understand the nature of their cancer risk and recommended methods of screening and prevention. Intervention strategies that address both structural constraints and patient-provider communication are needed to improve GC communication with immigrant Latinas, especially monolingual Spanish speakers.

Keywords Genetic counseling · Hereditary breast cancer · Latino · Hispanic · Immigrant health · Public health genomics

Introduction

While only a small percentage of women who get breast and ovarian cancer have deleterious *BRCA* gene mutations (5–10 %), the threat to these women and their family members is severe. They have as much as an 84 % lifetime risk for breast cancer and 63 % lifetime risk for ovarian cancer (King et al. 2003). Counseling, screening, treatment, and preventive measures associated with *BRCA* testing have been shown to reduce morbidity and mortality and to improve quality of life (Domchek et al. 2010), and thus, genetic counseling (GC) and testing for individuals and families at risk of hereditary breast and ovarian cancer (HBOC) are the standard of care (NCCN 2013). Yet, as genetics and genomics become mainstream medicine, these advances can actually exacerbate breast cancer disparities if low-income women are unable to access and benefit from genetic risk services in the same ways as those who are affluent and insured. Fewer than 13 % of all women who receive *BRCA* testing in the USA are of non-European ancestry (Hall et al. 2009) even though people of color, who are disproportionately low-income, make up 37 % of the US population. A study by Hall and colleagues showed that Latinos[1] represented only 4 % of the population tested

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[1] We use the term Latino or Latina except when citing works that use the term Hispanic, as Latino appears to be the preferred term used by the Mexican and Central American participants in our study.

between 1996 and 2007, despite being the largest minority in the USA, comprising ~12.5 % of the population in 2000 (US Census Bureau 2000) and 17 % currently (US Census Bureau 2013).

Breast cancer incidence and mortality rates for Latinos are lower than for whites and African Americans (Siegel et al. 2013). Recent studies, though not definitive, indicate that the prevalence of *BRCA* mutations may be higher than other populations (John et al. 2007; Weitzel et al. 2013). For example, Weitzel and colleagues found a 25 % prevalence rate among primarily Mexican origin Hispanics in his clinic-based study of 746 individuals (Weitzel et al. 2013). Despite their risk, Latinos' awareness of hereditary causes of breast cancer, genetic testing, and counseling services is limited (Gammon et al. 2011; Ramirez et al. 2006; Vadaparampil et al. 2006). Still, Latinos of different national origins appear to be interested in breast cancer genetics services (Ramirez et al. 2006; Sussner et al. 2010) and, when offered, accept them at high rates (Lee et al. 2005; Ricker et al. 2006).

Nevertheless, access to these services is limited. The patchwork health insurance system in the USA combined with the issue of who is able to access health care services and where, including genetic testing and counseling for breast cancer, reflects US norms of race and class stratification (Nelson 2011; Omi and Winant 1986; Washington 2007). As a result, people of color are overrepresented among the poor and the uninsured, and they thus disproportionately seek care in public "safety net" hospitals and clinics (Hasnain-Wynia et al. 2007; Haynes and Smedley 1999) where typically two thirds of the patients are minorities (Regenstein and Huang 2005). The provision of *BRCA* counseling, testing, and follow-up services in such safety net settings is uneven, limited, or nonexistent. Medicaid (the federally funded health insurance for the poor) covers genetic counseling and/or testing for hereditary cancer in only 26 of 50 states (FORCE 2011), and Medicare, the federal insurance for those aged 65 and older, covers genetic testing but not genetic counseling for breast cancer. It remains to be seen how health reform (the 2010 Affordable Care Act), which requires insurance to cover *BRCA* testing for unaffected women as a form of prevention (Obamacare Preventive Care 2010), will impact accessibility of these services. Furthermore, while financial access is essential, it is not itself sufficient to ensure high-quality genetic counseling and testing. When these access barriers are overcome, effective communication with genetic counselors is needed.

Gaps in *effective communication* (when a message reaches the intended audience and where the meaning is mutually understood) are widely recognized as a major contributor to health disparities (Thomas et al. 2004; US Department of Health and Human Services 2000). It is also well established that language barriers contribute to health disparities for limited English-speaking patients (LEP) and that the use of trained medical interpreters can improve care (Jacobs et al. 2003; Karliner et al. 2007). According to a recent study, almost 26 % of Hispanics either speak English "not well" (16.9 %) or not at all (9 %) (Ryan 2013). Furthermore, low health literacy affects 36 % of Americans and is disproportionately found among those with less education, living in poverty, and/or of ethnic/racial minority background (Kutner et al. 2006; Nielsen-Bohlman et al. 2004). As defined in *Healthy People 2010*, health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"—and includes not only print, oral, and numeracy capabilities but also cultural/conceptual knowledge (US Department of Health and Human Services 2000).

GC communication consists of four key components: (i) elicitation of family history; (ii) education about genetics, cancer risk, and risk reduction strategies; (iii) counseling/psychosocial support; and (iv) informed consent for genetic testing (GT) (Riley et al. 2012; Roter et al. 2007). Given the documented role of communication in health disparities, it is essential to elucidate how effectively counselors are able to deliver these key components of GC communication with their underserved patients and to elicit and understand the varied concerns, beliefs, and information needs patients have. To date, relatively little research on genetic counseling communication regarding genetic literacy and medical interpretation has been conducted, and little has included underserved patients or analyses of underserved subgroups (Erby et al. 2008; Lea et al. 2011; Roter et al. 2007). Research with Latino patients has primarily been conducted in the prenatal rather than cancer genetics setting. Some of the issues of culture, language, and literacy raised in that literature may be relevant to cancer counseling, including the potential confusion and misunderstanding due to the counseling tenet of nondirectiveness (Browner et al. 2003; Penchaszadeh 2001; Rapp 1993), use of medical jargon, inadequate translation, patient mistrust, counselor's misplaced cultural sensitivity (Browner et al. 2003), and varied formats for presenting risk information (Eichmeyer et al. 2005). This pilot study begins to address these important gaps in understanding cancer genetics communication with low-income Latinas.

Methods

Setting and population

The data for this paper were gathered at a public safety net hospital (SNH).[2] Like many hospitals that make up the health

[2] We use "SNH" throughout to protect the identity of counselors and patients.

care safety net in the USA, SNH is publicly owned and serves many patients who have no medical insurance or are covered by Medicaid or Medicare. Located in an urban area, SNH serves more than 100,000 patients annually and is affiliated with an academic medical center whose faculty and staff provide clinical and teaching services at SNH, including genetic counselors.

Recipients of HBOC counseling and testing reflect SNH's diverse population. Latino patients (primarily Mexican and Central American) make up about 25 % of all patients seen by the cancer genetic counselors at SNH and comprise 31 % of the population served by the SNH overall. Two part-time master's level genetic counselors (GCs) see patients in the general oncology, breast, and gynecological oncology clinics. During the period of our study, genetic counseling interns (master's students in genetic counseling) conducted or helped to conduct 10 out of the 28 sessions we observed, including 9 in Spanish. Genetic counseling and testing are available to patients free of charge at SNH through a variety of means, including foundation support, MediCal (the state's Medicaid program), Medicare, Myriad Genetic's hardship program, and a multisite research study (unrelated to the present study). During our study, most Latino patients were offered testing through the multisite research study focused on Latino patients (Weitzel et al. 2013). [3] Consent for the testing study was conducted by the genetic counselor during the session and was not part of the consent process for our study's observations and interviews which were conducted by the second author.

Data collection

Qualitative methods informed by the anthropological approach of ethnography were used, including direct observation of genetic counseling sessions and interviews with patients after they received genetic test results (Higginbottom et al. 2013). All research procedures for this study were approved by appropriate Institutional Review Board. In accord with our IRB-approved protocol, in this paper, all proper names are pseudonyms. We have changed some potentially identifying characteristics of locations and individuals as these are largely incidental to the substance of this paper.

Data were collected from October 2011 to February 2012 during direct observation of genetic counseling appointments and interviews with patients. All genetic counseling appointments with self-identified Latina patients who had appointments when the research associate was available were eligible for inclusion in the study. Therefore, there may have been other eligible participants who were not offered the opportunity to participate. The observer took detailed field notes to record the dynamics of the session, communication challenges, emotional content, body language, etc.

Observed participants who were offered genetic testing were invited to participate in an interview after they received their test results. In addition, the GCs identified five patients we had been unable to observe who agreed to participate in interviews. We conducted 10 interviews with patients in the patient's preferred language, $n=9$ in Spanish and $n=1$ in English, after their result appointment, using a semistructured protocol that allowed participants to introduce substantive topics not anticipated by the interviewer and to address topics in their own words and manner (Berg 2007a; Fetterman 1998). Interview topics included the following: (1) subjective experience with genetic counseling, (2) communication with counselors, (3) understanding of breast cancer inheritance, (4) risk perceptions and understanding, (5) interpretations of testing and posttest cancer screening recommendations, and (6) personal/family history (see supplementary material: Interview Guide). Interviews and observations were conducted by the second author, a highly trained, master's level, bilingual bicultural Latina researcher. Standard ethnographic techniques designed to minimally disrupt patient's usual routines were used to conduct systematic observations (Atkinson and Hammersley 1994; Denzin and Lincoln, 1998; Johnson and Sackett 1998; Joseph and Dohan 2009). These standard methods were selected to ensure that the research did not affect the care received by participants, that the data reflected usual care routines, and that there was minimal disruption to these routines. Furthermore, as a teaching hospital, the presence of student and other observers was common. We obtained written informed consent for all interviews. Interviews were digitally recorded and translated/transcribed verbatim for analysis by a professional transcriber. All interview participants were compensated for their time with a $25 grocery store gift card.

Data analysis

We utilized content analysis to code and analyze our data, reading through our data (observation field notes and interview transcripts) multiple times to identify key themes that recurred in field notes and transcripts (Berg 2007b). The two coauthors independently coded the data for its substantive content and met regularly to refine and reconcile codes. We used Atlas-ti to manage the text data and attachment of codes. The key themes we identified are presented here.

[3] Positive test results were confirmed through a commercial laboratory; negative test results reflect the research test which included common mutations in the Hispanic population, rather than full sequencing. Since the end of our study, some of the patients who tested negative on the "Hispanic panel" (Weitzel et al. 2005; Weitzel et al. 2013) during our study have been called back and re-tested with an expanded research panel or full sequencing and deletion/duplication analysis at a commercial lab. In a few cases, patients who previously received negative results subsequently tested positive.

Results

Participant characteristics

A total number of 25 patients participated (one eligible patient declined to participate). We observed 20 patients during 28 genetic counseling appointments (seven in more than one appointment). Out of the 20 observed participants, 16 (80 %) were monolingual Spanish speakers. Those who received genetic counseling in Spanish received it via a professional medical interpreter, other hospital staff (genetic counseling assistant, navigator, or resident), a family member, or directly through the GC intern who spoke Spanish (nine sessions). The four bilingual patients who received their counseling in English had varying levels of English proficiency.

Demographics of interview participants (n=10) are detailed in Table 1. They were immigrants from Mexico, El Salvador, and Guatemala with varied immigration status and education levels, and ranged in age from 38 to 87. Eight received counseling in Spanish and two in English. While four women had been previously diagnosed with cancer, six had no personal history of cancer and were referred by the SNH mammography clinic or a primary care provider due to family history. All had received *BRCA* testing (nine research study/one full sequencing) at the time of the interview; nine were negative and one was positive. Demographics of observed patients were similar to those we interviewed and reflect well the women typically seen in SNH cancer genetics program. The two participating counselors were both white women and experienced counselors who had been in practice at the SNH for several years (and longer in other settings). The GC interns were second year master's students in genetic counseling and were white and Asian women. None were native Spanish speakers.

Themes

Analysis of the observation field notes and patient interviews identified both strengths and limitations of current GC communication practices which we present in the context of the following six themes: (1) family health history communication; (2) education regarding genes and genetics and patient information needs; (3) the purpose of the genetic test (and patient motivation to take it); (4) genetic test results and cancer risk, to worry or not to worry; (5) building rapport and providing support; and (6) medical interpretation for monolingual Spanish speakers.

Family health history communication

A key component of genetic counseling communication is the counselor's elicitation of the patient's family history. This can be a challenge in any family but may be more complicated for immigrants who come from countries ravaged by war or places where medical care was rarely accessible and thus the causes of death were frequently unknown. For 38-year-old Rosa, gathering information the counselor requested about her sister's ovarian cancer from her family in Mexico was difficult, and that difficulty caused her to feel embarrassed with the GC.

Table 1 Interview participant demographics

Interview no.	Age	Breast cancer status	Country of origin	Immigration status	Time in the USA (years)	Education	Marital/family status	No. of times observed	Language of counseling
QI-1-LW3	42	Metastatic BC	Guatemala	Citizen	20	Unknown	Married with three children	2	Spanish
QI-2-LW10	38	Unaffected	Mexico	Undocumented	4	College/Bus. Admin	Single	3	Spanish
QI-3	37	Unaffected (*BRCA*+)	Guatemala	Undocumented	3	Less than elementary	Divorced with one child	0	Spanish
QI-4	45	BC remission	Mexico	Citizen	20	Less than elementary	Divorced with two children	0	Spanish
QI-5	39	Unaffected	El Salvador	Citizen	26	High school	Single	0	English
QI-6	48	Unaffected	Mexico	Undocumented	5	Some high school	Married with two children	0	Spanish
QI-8-LW5	36	Unaffected	Guatemala	Undocumented	17	College	Married with two children	3	Spanish
QI-10-LW7	50	BC remission	Guatemala	Legal resident	21	Elementary	Divorced with five children	3	Spanish
QI-11-LW11	54	Unaffected	El Salvador	Legal resident	52	Some college	Divorced with one child	2	English
QI-12-LW12	87	BC remission	El Salvador	Citizen	52	College	Married with six children	1	Spanish

> We talked about family, about my whole family, about my parents, everyone, about the generations. [The counselor] asked me if I could give them all to her. I was so embarrassed that I couldn't say—How could that be? [QI-2-LW10][4]

Cultural beliefs about cancer also played a role in Rosa's and other patient's family communication about health history. Rosa reported that her aunt had died from stomach cancer. When the GC asked if it was possible that her aunt's cancer might have started in another part of the body such as the ovaries (which would have raised the counselor's risk assessment significantly), Rosa said that she did not know. She explained that her aunt was a nun and did not want people to know that she had cancer because for her, it was like *un pecado* (a sin). Cancer was seen as *una maldición* (a curse) for something she had done. Thus, the family had only learned about the aunt's illness when she was dying.

One of the communication strengths of the counselors in our study was their ability to convey the purpose and importance of examining the family medical history. They took in stride patients' limited family history knowledge and expressed understanding of the difficulty obtaining information about family history. They would offer encouragement and advice on strategies for talking with family members and would often schedule a second appointment before making a full-risk assessment (and deciding whether to offer genetic testing) to allow time for the patient to gather more of the family's health history. In this way, the GCs involved the patients in the process of building the family history by encouraging family communication around cancer. They also utilized particular strategies to elicit the family history from patients with low health literacy (e.g., patients who lacked knowledge of anatomy or of cancer and how it spreads). For example, by asking questions about the treatments undergone for a relative's cancer and the time between diagnosis and death, they were able to better assess if the cancer was ovarian, cervical, endometrial, or stomach cancer, and thus identify or rule out ovarian cancer, which is rare but significantly increases the likelihood of a hereditary cancer syndrome linked to *BRCA*.

In some cases, the GC used the drawing of the family history (pedigree) she made during the session to explain the patterns she had identified and their significance.

> What helped me was that…so she started to make the drawings and putting my mom on one side and my dad on the other side. So, also, if, if I were to have a disease, my kids could also inherit it. That's what, that's what helped me [to understand]. [QI-6]

> It is that she made for us little drawings and everything, she would tell us, where they came from, from the mom, and from the dad, and she would draw for us, well everything,…Because she answered all of our questions, and she would do it with little drawings, she would do so that we would understand. [QI-4]

These and other patients appreciated when the counselor showed and explained the pedigree drawing, rather than just using it for her own assessment and records.

Education regarding genes and genetics and patient information needs

The counselors typically began a session by asking if the patient knew why she was referred, or what her understanding was for the appointment, and then offered the patient an opportunity to voice her concerns and/or wishes for the session (a process referred to as "contracting") (Bennett et al. 2003). Most participants we observed were referred with little or no prior knowledge or awareness of genetic counseling or testing for breast cancer and with little explanation from the referring provider. One patient, who had told the counselor that she did not know the reason for her appointment, described in her interview how she understood her doctor's referral:

> Participant (P): Through Dr. J., since I told him that so many people in my family have died of cancer, my dad's sisters, he said, "How does it sound to you if we referred you to a genetic doctor?" "Sure. No problem." So he says, "Well, good." He said, "Don't worry, it's not because you have it, but rather so you can learn about the process, or how to deal with it in the case there's cancer." "Ok, that's fine."
>
> Interviewer (I): What was your understanding when Dr. J. referred you? What did you think would happen when you went to see the genetic counselor?
>
> P: It was so I could help my family, right, because they were going through- well, we were all going through something really hard, right? So, it was to see if I could help my sister more, since she's my twin. So, she's feeling everything, and I'm feeling it too. [QI-2-LW10]

As in this case, even when the doctor offered an explanation, patient's understanding of what it meant to talk with a genetic counselor was quite vague. However, the motivation to attend the appointment in order to help her family was common among many of the patients in our study.

After obtaining a patient's family history, the GC would usually explain HBOC contrasting it with "sporadic cancer or

[4] This notation identifies the interview (QI) and the observation (LW). In cases where only one notation is present, only an interview or an observation was conducted, but not both.

cancer that happens by chance." For example, as recorded in our field notes,

> The GC said that she wasn't sure why [the patient's] sister got cancer or if her doctor's explanation is correct or not, but most of the time when people develop cancer it just happens by chance and is not related to genetics, to family history. It is not caused by any one particular reason. [QI-8-LW5]

> The GC said that she wanted to talk with Sara more about the option of doing a genetic test to find out if her cancer was due to a hereditary risk factor. She continued, cancer is common, but in a small number of families it is hereditary. Risk factors put family members at a higher risk of developing cancer. When talking about hereditary breast cancer, the GC said she is talking about two genes that can change and therefore put the person at a higher risk. The GC asked Sara if she had heard of the genes. Sara said that she hadn't. [QI-10-LW7]

Despite counselor's efforts to assess patient awareness and knowledge, their explanations of concepts such as hereditary risk factors and the role of the *BRCA 1* and *2* genes were sometimes not accessible to the patient. For example, Sara, a 5-year breast cancer survivor, misunderstood the counselor's explanation and thought the GC was talking about her cancer. As recorded in our field notes:

> The GC said that in our bodies we have billions of cells and inside every cell there are a 'bunch of' genes, a lot of different genes. Genes are like an instruction book that tells our body how to grow and develop. Our genes are why we look like our family members. Genes determine the color of our eyes or hair that we will have. We also have genes that protect us from developing cancer. These genes are something that everybody has, but if there is a mutation or a change it puts people at a higher risk of developing certain cancers. The GC asked if what she was saying made sense to Sara and if she had any questions. Sara hesitated and appearing confused, asked: 'When they cut out the lymph nodes or a part of them?' [QI-10-LW7]

In response, the GC tried to explain again that she was talking about genes in the body that can put a person at a higher risk for cancer and that this was different than talking about cancer in the body spreading to the lymph nodes. However, when she asked again if Sara understood, Sara simply nodded. It was clear from her interview that she did not understand what the GC had explained; nevertheless, she did comprehend the GC's take-home message that her negative test result meant she did not need to worry about her daughters and granddaughters.

In interviews, we asked participants what they understood about genes and the role of genetics in cancer. Although most participants could not report what the counselors had explained about the *BRCA* genes and genetics, importantly, at least in some cases, it did not appear to be a matter of retention but rather a lack of understanding at the time of the counseling. For example, Nora, who had not completed elementary school, said

> I only knew that they were going to take blood and they were going to do so for a genetic test. But she already started to explain to us, um, I don't know how to say it to you…*but I tell you that there are words that one does not understand.* [QI-4]

A patient's higher educational achievement did not always facilitate a better understanding of genes and genetics. One participant with a degree in business administration from a college in Mexico also had a poor understanding. When asked about the *BRCA* genes, she hesitantly explained,

> It's like there are two types of blood, right? And- well, that's how I understood it, that it's like there are two types of blood, and that one of them seems to be stronger than the other, right? And that's what tells you where the cancer is. Ahhh, that's how I understood it, I don't know if that's how it is, right, but in short, that's what it is to me. [QI-2-LW10]

As in the previous two cases, the material presented by the counselor was typically new to the patient. On one rare occasion that provides a contrast, a woman with recently diagnosed advanced breast cancer had spoken with a social worker about genetic testing prior to her counseling appointment and seemed to have a better, if not entirely correct, understanding of what the counselor explained,

> A gene? It seems that a gene is something in your blood that gets transmitted. Like we pass on our blood in our own family it gets passed on like that. That's what I think. [QI-1-LW3]

Although GCs asked patients frequently during the GC sessions if they had questions, patients often said "no," and when asked if they understood they often said "yes." When patients did ask questions, they tended to be focused on how a positive test result would affect or benefit their family members.

> I: So when you were speaking with the genetic counselor, if you didn't understand something, what would you do?

> P: I didn't ask. Because I was embarrassed. Because I was embarrassed.

I: Uh-huh. When you go to the doctor in general, do you ask the doctors questions?

P: Yes. Yes.

I: Yes. So why were you embarrassed with the genetic counselor?

P: Actually I don't…I don't really know why I was embarrassed to ask her. [QI-6]

It was clear from her interview that this patient thought that the test would tell her if she had cancer or not, and she was ready to start treatment if the test was positive, even though she was not sure what type of treatment it would be: "Whatever they gave me. Whatever they said. Yes." Despite such misunderstandings, all observed patients who were offered the test accepted it, and in interviews, most said they were motivated to take the genetic test to obtain information that might help protect them and/or their family members from cancer, as discussed further in the next section.

The purpose of the genetic test (and patient motivation to take it)

Despite often not understanding the counselor's explanation of genes and genetics, many of the participants did garner a basic understanding of the purpose of the *BRCA* test. For example, when asked about her understanding of the purpose of the test, one patient responded:

It tells the probability of getting cancer…I asked her what it is really for. And she said it was to see where they could give you a probability, right, of having a—something-like cancer, or something like that, and that would help me rule out the idea, right, yeah. That's what I understood. [QI-2-LW10]

She just said that, that if I agreed, I mean if I wanted to get an exam, if I wanted that to, they said basically to study my genes and what is the probability so they could see if I would get cancer or not. [QI-6]

As with the latter, some patients interpreted the explanation of the test's purpose in more definitive terms than the counselor's description indicated—understanding the test as predictive of cancer, rather than predictive of the risk of cancer. As another participant said, the purpose of the test is "To know more about the disease, whether you're going to get it or not." [QI-10-LW-7]

Patients generally understood the potential benefits of testing as described by the GCs (to help the GC and other providers keep the patient and her family healthy) and were consistently motivated to take the test in order to help their children, their sisters, and themselves.

And also to find out what I could tell my kids. So the same thing, if I were to end up with some disease, my kids would have to get tested because they could also inherit it. [QI-6]

Although the general prevention message offered by the GCs was understood, the details of "prevention" (risk reduction via surgery) or early detection through screening (alternating MRI and mammography every 6 months) were not often discussed in detail prior to testing.

Genetic test results and cancer risk: to worry or not to worry

We observed that the counselors aimed to communicate the three possible results (positive, negative, or variant of uncertain significance) by clarifying the meaning and limitations of the test results for each patient in the context of her personal and family history of cancer. To do so, the counselor would often simplify the take-home message into a question of whether the patient would need "to worry" or "not to worry" and then would explain the estimated risk using subjective rather than numerical terms, such as "the same as the rest of the population" or "slightly higher than the general population." If a patient had already been diagnosed, the patient's diagnosis would be incorporated into the risk assessment.

For patients with a negative test result that the counselor interpreted as *no need to worry* about an increased risk, the GCs still recommended regular screening with annual mammography beginning at age 40 and annual clinical breast exams, in accord with National Comprehensive Cancer Network (NCCN) guidelines. Yet, patients could not always hear the GCs' screening recommendations in the moment of relief that the genetic test was negative.

…as soon as she told me that everything was okay, I didn't feel like asking anything more. I didn't say anything. That was what I was hoping to hear. …And I had an interpreter there who was telling me that everything was okay and asked if I had any questions. No! After that I just wanted to leave. [QI-6]

Interviews with patients who had received negative results also identified uncertainty and confusion about the meaning of negative test results. For example, the patient quoted above who was eager to leave the appointment immediately after getting her test result, misunderstood the *BRCA* test as a diagnostic exam that she would repeat periodically to make sure nothing had changed.

…they've given me a diagnosis that I'm okay, but you never know. The results—for example, I got them 6 months ago. A lot of things can happen in 6 months. If during those 6 months, even though it came out

> negative 6 months ago, it could come out positive. You never know. We have to be realistic. [QI-6]

One of our English speaking participants, Olga, understood that she was not at increased risk, but she did not understand what that meant for her children and grandchildren.

> I think the biggest question, which I don't even know if there is an answer to it, is like how can you get to know if this is going to affect your kids and grandkids. You know, I'm in the clear as far as this particular little gene, you know, and hopefully, you know, from what [the GC] explained to me, it shouldn't-you know, maybe it diffuses or gets diminished as the generations come along. So for me, that's a big peace of mind. [QI-11-LW11]

Despite the GC's explanation that Olga's risk was "the same as the general population," she and other participants assumed that they had no breast cancer risk.

> I: Do you still see yourself as being at risk of having breast cancer?
>
> P: I don't, I really don't, maybe someplace else but not in my breasts, maybe not in my breasts but, you know, who knows? Like we were talking when we got the results, it's like it doesn't mean that it can't happen someplace else, you know. But at least I don't have that, which is great. It would be great to have like a total screening where you don't have any cancer genes at all, but that's not a possibility right now. [QI-11/LW11]

One patient, Eva, with recently diagnosed breast cancer had been quite reluctant to test when the idea was first introduced because she was still reeling from her diagnosis and was afraid to get any additional bad news. Eva was very relieved—for herself and her daughter—to hear that the results were negative. However, it was not clear how well she understood the implications of her risk related to her metastatic breast cancer or that the *BRCA* test she underwent was part of a research study (and not the full sequencing), and thus, the result was not as definitive as she characterized it during her interview:

> That was all I needed to know. It was very clear that it wasn't genetic. There was nothing else to understand or think, or worry about.…She told me that there was less probability of having another type of cancer, the probability that one of my children—she gave me the positive reasons for the results to be negative. …I feel such a peace, like I said it's one less thing to worry about. *We threw it out once and for all.* That's why on the one hand it's good that I did it because I would still be wondering if I didn't do it. [QI-1-LW3]

Ana, the only woman in our study who received a positive *BRCA* test result, clearly understood that she did not have cancer and that her positive result meant that she had to keep up with all her exams, take care of herself, and tell the doctors if anything "didn't feel right." [QI-3] She said the GC told her:

> If it came out positive it didn't, it didn't mean that I had the disease, that I already had it. But rather it would mean that that I was positive, like a lot of other people. But a lot of people don't get it even like that…the ones who are susceptible or those who actually get it, there are a lot of medical possibilities now, and there are a lot of cases where they've removed ovaries or breast so that, to prevent it because those are the places where the disease attacks most. [QI-3]

A monolingual Spanish speaker, Ana, was pleased with the counselor's ability to anticipate and answer her questions through the interpreter during the test results counseling session.

> They had a translator there and what they were saying was like correct, like there were hardly any questions because, like, like the questions I would have in my mind, she would be answering them….maybe in my mind when I left the house, I had questions. So those questions I had, they were ready to tell me. [QI-3]

Ana's solid understanding was likely influenced by the fact that she had met with the GCs several times due to her positive test result and also because she had taken care of her 38-year-old *BRCA+* sister while she was dying from breast cancer, and with whom she was emotionally close. As a result, she had many more opportunities to be exposed to the information than other study participants. Patients who test positive also receive a binder with information and resources at their results appointment. Unfortunately, these materials are in English, except for a DVD about hereditary cancer which is available in both English and Spanish.

Building rapport and providing support

In addition to providing education, a key component of genetic counseling is the provision of psychosocial support. We found that counselors were particularly effective in building rapport and providing support to English speaking patients. For example, Olga said,

> …she communicated everything really really well, where I understood where she was going. …I *was understanding maybe too much and I thought oh God,*

> *what if I do have that gene?*…she was very very good about explaining and I understood that there was that possibility of something. She made it clear. [QI-11-LW11]

And later in her interview:

> …you know, it's a nice support system. It's very personal and you feel comfortable. There's nothing to be scared about, you are not really scared. Maybe apprehensive, a little bit wondering. [QI-11-LW11]

We also observed that counselors effectively provided reassurance to patients who feared a positive test result.

> I didn't feel sad, but rather a little bit scared to think that I could get…And the GC also had, had some advice for me. She said, "you don't have to be scared because… don't think that its going to turn out that you inherited the gene from your mom. Let's wait and see what the results show. [QI-5]

> …they had a lot of patience and she would answer all of our questions and was explaining everything to us very well…what was what one would want to know, right, and with that what I could do to help my sisters in doing those tests if it came out positive. [QI-4]

In another case, the patient became very upset during a counseling session as the GC explained the possible test outcomes. The counselor was able to effectively reassure this patient. From the field notes,

> When Rosa started sobbing, the GC asked her to share what she was feeling, but she couldn't answer for a while. Then the GC asked if it was scary for her to think about it. Rosa said that what hurt her the most was that she doesn't have children and she was thinking about getting pregnant this year. "I don't know if I am going to be able to have children "ya no soy jovencita. Ya tengo 38 años." (I'm not so young anymore. I'm already 38.) That is what hurts the most, she said. The GC said that she could see how that could be worrying, but that the likelihood is that the test would be normal and it won't be something she will have to worry much about. But, even if the test were positive it doesn't mean that she couldn't have a baby; it doesn't mean that at all…" [QI-2-LW10]

Rosa also was afraid that if she had a baby, the baby would have cancer. The GC explained that if she carried the cancer gene, there was a chance that the child would develop cancer but that it would not affect him or her for many decades; these were not cancers that affect children. The GC also used the opportunity to reiterate the concept of risk with respect to cancer development and the value of the test as a way keep her healthy. The GC's explanation made the patient feel calmer, and the conversation moved on to a discussion about the genetic test.

In another case, we observed a mismatch between the GC's offer of additional information to reassure a patient and the patient's need for something else. Eva, a monolingual Spanish-speaking mother of three young children, was reluctant to test for the *BRCA* genes because she was afraid of receiving more bad news after her cancer diagnosis. After acknowledging the patient's distress upon hearing that her cancer might have spread to the liver, the GC asked, "is genetic testing something you are interested in doing?" Eva said, "tanto, tanto como interesada, no" (really, really interested, no). In the face of Eva's reluctance, the GC explained why it would be good to know—that "if negative, we wouldn't have to worry about your family" and "if positive, we would be able to do extra screening." However, this information was preceded by, and seemed to get lost in, an explanation of the *BRCA1/2* genes, gene mutations, and the counselor's attempt to reassure the patient by conveying her expectation that the result would likely be negative. When the GC concluded, and after the video interpreter connection had been turned off, Eva looked at her husband and mumbled, "I am going to do it so they leave me alone."

Medical interpretation for monolingual Spanish speakers

The quality of Spanish interpretation varied significantly, and at times was not adequate for the patient to fully access the benefits of genetic counseling. State law requires professional medical interpretation to be provided; at SNH, interpretation is available and provided by the hospital primarily via videoconference medical interpretation (VMI) or telephone. During the course of our study, we observed interpretation being provided by a range of individuals who had varying skill levels, including the professional medical interpreters via VMI or phone, in person via staff (genetic counseling assistant, patient navigator, volunteer medical resident), family members, and genetic counseling (master's level) student interns.

With regard to the professional medical interpreters, we observed some barriers to optimal communication between counselor and patient. Professional interpreters were sometimes unfamiliar with genetic counseling, including the hour-long initial appointment, some specific vocabulary, and the nature of genetic information. For example, during one appointment we observed, well into the counselor's explanation of hereditary cancer and the *BRCA* genes, the interpreter ask: "Are you a genetic counselor?" We also observed professional interpreters translate probabilistic statements as definitive statements. In one instance, the GC said the patient's cancer was "probably not the result of genetics" and the interpreter

translated it as "the cancer was not caused by genetics but rather was something "aleatorio." The interpreter thus not only added his own explanation to the GC's statement, but employed a rarely used mathematical term for "random" that few low-literacy patients are likely to know. In other cases, we heard the interpreter change and shorten statements that changed the meaning. For example, when a counselor told one patient that "5–10 % of breast cancer is hereditary," the interpreter said "10 % of breast cancer is hereditary."

The use of the VMI frequently presented technical problems, particularly the inability for all parties in the conversation to hear one another. As a result, the provider sometimes had to shout and repeat herself; in such circumstances, the GC would often shorten her statements, thus reducing the explanation and educational content she offered to the patient and making it more difficult to use the range of affect customary to counseling. Such difficulties also occasionally led the GC to let the interpreter go before the end of the session, for example, before the patient has signed the consent for testing or for participation in an ongoing follow-up research study offered to all patients who undergo genetic testing at SNH.

Due to these difficulties with the professional interpretation available, the GCs sometimes preferred to use their own staff, other hospital staff, or students as interpreters, who could be present in person. For example, the counseling program attempts to keep on staff a genetic counseling assistant (GCA) who is bilingual in Spanish. However, this was not always possible and the level of fluency of the GCA varied during the period of our research. The advantage of having a bilingual GCA perform the interpretation is their knowledge of genetics, familiarity with the genetic counseling process, and their availability in person. However, they are not trained as interpreters. Similarly, patient navigators who occasionally accompanied the patient might perform the interpretation (patient navigators are trained, culturally sensitive health care workers who provide support and guidance throughout the cancer care continuum) (Robinson-White et al. 2010). Although not trained as interpreters, patient navigators are familiar with breast cancer, know the patient and clinic, and can act as a cultural broker as well as a translator. One genetic counseling student intern who spoke conversational Spanish very well but was not fully proficient also led several sessions we observed and once provided interpretation for the counselor. In this instance, the patient mentioned to the observer after the appointment that she felt offended that she had been given an interpreter "who didn't speak Spanish."

Finally, it must be noted that not all patients who could benefit from interpreters accepted them. For example, one of the patients we observed refused an interpreter because she felt confident that she could communicate with the GC in English; however, we observed communication difficulties due to language during her session. Counselors were aware of this problem but were not sure how to address it without offending the patients who declined the offer of an interpreter.

Discussion

As genetics and genomics become mainstream medicine, these advances can actually exacerbate breast cancer disparities if low-income women are unable to access and benefit from genetic risk services in the same ways as those who are affluent and insured. While Medicaid has begun to reimburse for cancer genetic services in many states, and it is likely that the Affordable Care Act will further the availability of genetic testing for HBOC, such financial access is essential but not itself sufficient to ensure the full benefits of genetic counseling and testing given that gaps in effective communication contribute significantly to health disparities (Thomas et al. 2004; US Department of Health and Human Services 2000). The number of patients testing overall, and those testing positive for hereditary cancer syndromes like HBOC is likely to increase as the number of genes tested increases with the utilization of next generation panel tests (Ormond 2013). This next generation screening will bring new opportunities for both benefits and increased disparities, as well as its own communication challenges.

This pilot study utilized qualitative ethnographic methods to identify key aspects of current communication practices in a public hospital that has been offering cancer genetics services for several years. The results identify both strengths and weaknesses in the genetic counseling that is available and begin to explain how and why miscommunication or ineffective communication occurs. As such the results provide evidence needed to guide further research and intervention development to improve the effectiveness of GC communication with low-income Latina immigrants in the public health setting. In contrast to other studies of genetic counseling with Latinas, which focused on acceptability of counseling, psychological outcomes, and *BRCA* test results (Lagos et al. 2008; Sussner et al. 2010), our study examined the actual communication dynamics between counselors and patients by observing the counseling sessions and interviewing the patients afterward. Our study included real rather than simulated patients (Roter et al. 2007) in the context of their care and focused on cancer GC rather than prenatal counseling (Browner et al. 2003).

Our observations and interviews identified strategies counselors are using to bridge differences in literacy levels, language, and culture. For example, the use of a second pre-test appointment allows patients time along with specific strategies for collecting additional family history and also provides a way for counselors to build rapport and to reiterate key information prior to testing. While this strategy may not be

applicable in all settings due to limited resources on the clinic side and limited ability to attend multiple appointments due to transportation and other logistical issues on the patient side, this strategy does reflect and respond to the patient's reality. Many patients do not have family history information immediately available or accessible due to health care in the home country, cultural issues that may limit communication about cancer, and low health literacy or numeracy that may limit understanding of cancer and cancer risk. The counselors were also often able to reassure patients by explaining that the test results would help the GC and the patient's other health care providers keep the patient and her family healthy. The GCs also utilized the pedigree they had drawn during the family history discussion to explain heredity. This technique, which appeared to be helpful, could be used more consistently.

Our findings also identified components of the communication that were not optimally effective. Some of the communication gaps resulted from structural constraints, most significantly the lack of consistently effective medical interpretation, which can impact all aspects of genetic counseling communication. While professional medical interpretation is required and available, it is not always implemented in an effective manner. Despite advances in technology that have increased the accessibility of interpreters via remote video and telephone, the quality of both the technology and people providing the services remain variable. Nevertheless, counselors can potentially increase the effectiveness of medical interpretation. Further research is needed to identify specific strategies that will improve the communication via interpreter such as the research on the benefits of orienting the interpreter to the genetic counseling appointment; offering the opportunity for interpreters to ask questions too if s/he doesn't understand a word or concept. Prior research has shown that professional interpreters compared with family members or other staff are more effective in other settings and this principal could be applied in genetic counseling (Karliner et al. 2007). In cases where a patient declines an interpreter, using the "teach back" method or other proven methods to assess patient understanding could be especially important (Schillinger et al. 2003; Sudore and Schillinger 2009).

Another structural constraint was the lack of trained master's-level bilingual/bicultural genetic counselors; 92 % of genetic counselors in the USA are white, and 86 % do not speak a language other than English. Only 5 % speak Spanish (NSGC 2012). While employing bilingual counselors in institutions serving large Latino populations might be ideal (Ricker et al. 2006; Lagos et al. 2008), the demographics of professional genetic counselors does not currently allow for this (Mittman and Downs 2008; NSGC 2012). The situation we describe in this article in which counseling is provided through interpreters who may or may not be adequately trained or only accessible remotely is likely representative of both the present and the near future. The GC student who conducted some of the GC sessions we observed in Spanish had strong informal conversational skills but was not proficient in the language overall. As in all health professional education, it is important to balance the needs of trainees and patient needs. A system is needed to assure that patients understand and are being understood as GC students use and develop their language skills (Vanneste et al. 2013).

Other components of communication where we identified challenges included communication of residual risk after a negative result. Up to 75 % of people with familial breast cancer who test for *BRCA* mutations receive uninformative negative results, yet they may still have an elevated risk compared to the general population (Metcalfe et al. 2009). Therefore, it is critically important to effectively communicate that risk and appropriate screening practices such as regular mammograms and clinical breast exams. As our data indicate, patients sometimes left their appointments with an inaccurate understanding of their breast cancer risk due to a misunderstanding of the nature of the test, i.e., as a diagnostic exam to be repeated periodically or as a more comprehensive and definitive test than is actually the case.

Our research also identified a mismatch between the patients' information needs and preferences and the information provided by the counselors. Although the GCs attempted to simplify their message substantially, they nevertheless seemed to provide more information about genes and genetics than most of the patients could understand and make use of. Patients appeared to be primarily concerned with the purpose of the test and how it might help them and their families. This raises questions about genetic exceptionalism—how different should genetic counseling be compared to other medical counseling? How different is a genetic test for the patient? How can we identify and meet patient's needs while also providing adequate information to meet the standards of informed consent for genetic testing? In the case of treatment options provided to cancer patients, protocols for informed consent do not generally include an explanation of the biological model underlying the treatments but rather their potential benefits, risks, and side effects. While genetic testing is not a treatment option but rather a measure of risk for the development of disease, it is unclear if the effort to convey the underlying biological model is any more necessary or of value to the patient than it is in the context of treatment offers or nongenetic risk assessment tests such as blood tests that indicate risks of heart disease in the form of cholesterol levels. Our findings would seem to suggest the opposite; patients seem neither to desire nor need this information to understand the concept of risk. At the same time, our data suggest that provider's efforts to explain the biology of genetic inheritance, no matter how simplified, can lead to confusion or crowd out the communication of other critical information, in particular for patients already dealing with the stress of a recent cancer diagnosis.

While this study provides important and novel insights, it has limitations. As a case study of one public hospital setting with only two counselors and a relatively small sample of patients, the results must be extrapolated to other situations with caution. Furthermore, the study focuses on low-income Latinas from Mexico, El Salvador, and Guatemala; the results may not reflect the experiences, needs, and realities of Latinas of other national origins or socioeconomic circumstances. The sample is too small to distinguish differences by national origin. Nevertheless, this study does provide a valuable first look at the communication patterns of GC to Latino women at risk for breast cancer. To address some of these limitations, a follow-up to this pilot study is underway and includes in-depth case studies of two public hospitals and patients who speak English, Spanish, and Chinese (Cantonese and Mandarin).

Our findings demonstrate the need to identify intervention strategies that are effective in improving communication with immigrant Latinas, especially monolingual Spanish speakers. Like the telenovela, which has proved effective in providing health information to Latinos (Elder et al. 2009) tools such as CREDIT, a short narrative video that explains hereditary breast cancer in simple terms (Joseph et al. 2010) could be used systematically before a patient's first appointment to prepare patients with baseline knowledge about genetic counseling and testing or be provided to take home to reinforce what the counselor said. Other tools and strategies used by GCs, such as the pedigree, could be used more consistently in daily practice as a visual aid to explain hereditary cancer and cancer risk in the patient's personal family history context. In the instances we observed in which the GC used it this way, patients were observed becoming more engaged in the process of discussing family history and expressed the view that it was helpful in understanding the concept of hereditary cancer.

Counselors also need strategies to ascertain how much patients understand so that they can adjust and tailor as they go. While they often ask, "do you have any questions?" many of the patients are reluctant to ask, do not know or understand enough to formulate a question, or ask questions that lack direct relevance to the immediate preceding topic of discussion. Patients in the genetic counseling context are often exposed to several new concepts with which they have little or no familiarity, and ongoing education outside of the two or three visits to a genetic counselor is unlikely to occur. Identifying key take-home messages, repeated assessment of a patient's understanding of those messages, and reiteration when required is a strategy that has proven effective in other health education contexts (Schillinger et al. 2003). Take-home information sheets with basic information about recommendations in Spanish may also assist. In interviews with the GCs who participated in this research and with other counselors at public institutions who were interviewed at the conference of the National Society of Genetic Counselors (NSGC) in 2011, GCs described a range of challenges in communicating with patients across literacy, language and culture. The results of those interviews coincide substantially with the findings described here and will be discussed in a separate paper. In addition, within the profession of genetic counseling, there is increasing acknowledgement of the need to address issues related to "multicultural counseling," as demonstrated by a recent special issue of the *Journal of Genetic Counseling* on diversity and cultural competence (Warren 2011), and a workshop on cultural competence at the 2011 Annual Education meeting of the National Society of Genetic Counselors.

In sum, strategies and interventions are needed (1) to further tailor educational components of GC for Latina women with regard to literacy and culture, (2) to facilitate effective collaboration with medical interpreters using any of the three medical interpretation modalities (video, phone, in person), (3) to deepen medical interpreters' understanding of the nature of the appointments and the technical language used during the genetic counseling to ensure consistent high quality interpretation, and (4) to identify and convey information that is both necessary and sufficient for patient understanding and ability to make informed decisions regarding genetic testing as well as prevention and screening recommendations.

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Compliance with ethics guidelines All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Conflict of interest Galen Joseph and Claudia Guerra declare that they have no conflict of interest.

References

Atkinson P, Hammersley M (1994) Ethnography and participant observation. Handbook of qualitative research. Sage, Thousand Oaks

Bennett RL, Hampel HL, Mandell JB, Marks JH (2003) Genetic counselors: translating genomic science into clinical practice. J Clin Invest 112(9):1274–1279. doi:10.1172/JCI20113

Berg BL (2007a) Qualitative research methods for the social sciences, 6th edn. Pearson Education, Boston

Berg B. L. (2007b) An Introduction to Content Analysis. In: Qualitative Research Methods for the Social Sciences 6th Edition. Boston, MA: Pearson Education, Inc

Browner CH, Mabel Preloran H, Casado MC, Bass HN, Walker AP (2003) Genetic counseling gone awry: miscommunication between

prenatal genetic service providers and Mexican-origin clients. Soc Sci Med 56(9):1933–1946. doi:10.1016/S0277-9536(02)00214-9

Denzin, N. K., & Lincoln, Y. S. (1998). Strategies of qualitative inquiry. Sage, Thousand Oaks, CA

Domchek SM, Friebel TM, Singer CF, Evans DG, Lynch HT, Isaacs C, Garber JE et al (2010) Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. JAMA 304(9):967–975. doi:10.1001/jama.2010.1237

Eichmeyer JN, Northrup H, Assel MA, Goka TJ, Johnston DA, Williams AT (2005) An assessment of risk understanding in Hispanic genetic counseling patients. J Genet Couns 14(4):319–328. doi:10.1007/s10897-005-0759-5

Elder JP, Ayala GX, Parra-Medina D, Talavera GA (2009) Health communication in the Latino community: issues and approaches. Annu Rev Public Health 30:227–251. doi:10.1146/annurev.publhealth.031308.100300

Erby LH, Roter D, Larson S, Cho J (2008) The rapid estimate of adult literacy in genetics (REAL-G): a means to assess literacy deficits in the context of genetics. Am J Med Genet Part A 146(2):174–181. doi:10.1002/ajmg.a.32068

Fetterman, D. M. (1998). Ethnography step by step (2nd ed.). Sage, Thousand Oaks, CA.

FORCE (2011). Advocacy organization. Finding specialists and paying for services : insurance, financial assistance, cost of services. http://www.facingourrisk.org/info_research/finding-health-care/financial-help/index.php. Accessed 3 January 2014

Gammon AD, Rothwell E, Simmons R, Lowery JT, Ballinger L, Hill DA, Boucher KM et al (2011) Awareness and preferences regarding BRCA1/2 genetic counseling and testing among Latinas and non-Latina white women at increased risk for hereditary breast and ovarian cancer. J Genet Couns 20(6):625–638. doi:10.1007/s10897-011-9376-7

Hall MJ, Reid JE, Burbidge LA, Pruss D, Deffenbaugh AM, Frye C, Wenstrup B et al (2009) BRCA1 and BRCA2 mutations in women of different ethnicities undergoing testing for hereditary breast-ovarian cancer. Cancer 115(10):2222–2233. doi:10.1002/cncr.24200

Hasnain-Wynia R et al (2007) Disparities in health care are driven by where minority patients seek care. Arch Intern Med 167:1233–1239

Haynes M, Smedley B (eds) (1999) The unequal burden of cancer, committee on cancer research among minorities and the medically underserved. Institute of Medicine, National Academy Press, Washington

Higginbottom, G., Pillay, J. J., & Boadu, N. Y. (2013). Guidance on performing focused ethnographies with an emphasis on healthcare research. Qual Report, 18(9). http://www.nova.edu/ssss/QR/QR18/higginbottom17.pdf. Accessed 10 June 2014.

Jacobs, E. A., Agger-Gupta, N., Chen, A. H., Piotrowski, A., & Hardt, E. J. (2003). Language barriers in health care settings: an annotated bibl iography of the research literature (pp. pp. 1–80.). Woodland Hils (Ca, USA): The California Endowment, 72. http://hablamosjuntos.org/pdf_files/Cal.Endow.Bibliography.pdf. Accessed 5 November 2013

John EM, Miron A, Gong G, Phipps AI, Felberg A, Li FP, West DW, Whittemore AS (2007) Prevalence of pathogenic brca1 mutation carriers in 5 us racial/ethnic groups. JAMA 298(24):2869–2876. doi:10.1001/jama.298.24.2869

Johnson A, Sackett R (1998) Direct Systematic Observation of Behavior. In: Bernard HR (ed) Handbook of Methods in Cultural Anthropology. Walnut Creek, CA, pp 301–331

Joseph G, Dohan D (2009) Recruiting minorities where they receive care: institutional barriers to cancer clinical trials recruitment in a safety-net hospital. Contemporary clinical trials 30(6):552–559. doi:10.1016/j.cct.2009.06.009

Joseph G, Beattie MS, Lee R, Braithwaite D, Wilcox C, Metrikin M, Lamvik K, Luce J (2010) Pre-counseling education for low literacy women at risk of hereditary breast and ovarian cancer (HBOC): patient experiences using the cancer risk education intervention tool (CREdIT). J Genet Counsel 19(5):447–462. doi:10.1007/s10897-010-9303-3

Karliner LS, Jacobs EA, Chen AH, Mutha S (2007) Do professional interpreters improve clinical care for patients with limited english proficiency? a systematic review of the literature. Health Services Research 42(2):727–754. doi:10.1111/j.1475-6773.2006.00629.x

King MC, Marks JH, Mandell JB (2003) Breast and ovarian cancer risks due to inherited mutations in BRCA1 and BRCA2. Science 302(5645):643–646. doi:10.1126/science.1088759

Kutner M, Greenburg E, Jin Y, Paulsen C (2006) The health literacy of America's adults: results from the 2003 national assessment of adult literacy. NCES 2006–483 National Center for Education Statistics http://filesericedgov/fulltext/ED493284.pdf Accessed 1(December 2013)

Lagos VI, Perez MA, Ricker CN, Blazer KR, Santiago NM, Feldman N, Viveros L et al (2008) Social-cognitive aspects of underserved Latinas preparing to undergo genetic cancer risk assessment for hereditary breast and ovarian cancer. Psychooncology 17(8):774–782. doi:10.1002/pon.1358

Lea DH, Kaphingst KA, Bowen D, Lipkus I, Hadley DW (2011) Communicating genetic and genomic information: health literacy and numeracy considerations. Public Health Genomics 14(4–5):279–289. doi:10.1159/000294191

Lee R, Beattie M, Crawford B, Mak J, Stewart N, Komaromy M, Esserman L et al (2005) Recruitment, genetic counseling, and BRCA testing for underserved women at a public hospital. Genet Test 9(4):306–312. doi:10.1089/gte.2005.9.306

Metcalfe KA, Finch A, Poll A, Horsman D, Kim-Sing C, Scott J, Sun P, Narod SA (2009) Breast cancer risks in women with a family history of breast or ovarian cancer who have tested negative for a BRCA1 or BRCA2 mutation. Br J Cancer 100(2):421–425. doi:10.1038/sj.bjc.6604830

Mittman IS, Downs K (2008) Diversity in genetic counseling: past, present and future. J Genet Couns 17(4):301–313. doi:10.1007/s10897-008-9160-5

NCCN clinical practice guidelines in oncology genetic/familial high-risk assessment: breast and ovarian. Version 4.2013. NCCN.org http://www.oncomap.org/download_zhinan/%E6%8C%87%E5%8D%97/genetics_screening.pdf Accessed 10 June 2014

Nelson A (2011) Body and Soul: The Black Panther Party and the Fight against Medical Discrimination. University of Minnesota Press, Minneapolis

Nielsen-Bohlman, L., Panzer, A. M., Kindig, D. A., (Eds). (2004). Health literacy: a prescription to end confusion. Washington, D.C.

NSGC (2012). Professional Status Survey: Executive summary.file:///Users/cguerra/Downloads/2012%20PSS%20Executive%20Summary%20(4).pdf Accessed 5 November 2013.

Obamacare Preventive Care. (2010, September 23). http://obamacarefacts.com/obamacare-preventive-care.php Accessed 31 December 2013.

Omi M, Winant H (1986) Racial Formation in the United States: From the 1960s to the 1980s. Routledge, New York

Ormond KE (2013) From genetic counseling to "genomic counseling.". Mol Genet Genomic Med 1(4):189–193. doi:10.1002/mgg3.45

Penchaszadeh VB (2001) Genetic counseling issues in latinos. Genet Test 5(3):193–200. doi:10.1089/10906570152742236

Ramirez AG, Aparicio-Ting FE, de Majors SSM, Miller AR (2006) Interest, awareness, and perceptions of genetic testing among Hispanic family members of breast cancer survivors. Ethnic & Dis 16(2):398–403

Rapp R (1993) Amniocentesis in sociocultural perspective. J Genet Couns 2(3):183–196

Regenstein M, Huang J (2005) Stresses to the Safety Net: The Public Hospital Perspective, Kaiser Commission on Medicaid and the Uninsured. Henry J. Kaiser Family Foundation, Washington

Ricker C, Lagos V, Feldman N, Hiyama S, Fuentes S, Kumar V, Gonzalez K et al (2006) If we build it … Will they come?—establishing a cancer genetics services clinic for an underserved predominantly Latina cohort. J Genet Couns 15(6):505–514. doi:10.1007/s10897-006-9052-5

Riley BD, Culver JO, Skrzynia C, Senter LA, Peters JA, Costalas JW, Callif-Daley F et al (2012) Essential elements of genetic cancer risk assessment, counseling, and testing: updated recommendations of the national society of genetic counselors. J Genet Couns 21(2):151–161. doi:10.1007/s10897-011-9462-x

Robinson-White S, Conroy B, Slavish KH, Rosenzweig M (2010) Patient navigation in breast cancer: a systematic review. Cancer Nurs 33(2):127–140. doi:10.1097/NCC.0b013e3181c40401

Roter DL, Erby LH, Larson S, Ellington L (2007) Assessing oral literacy demand in genetic counseling dialogue: preliminary test of a conceptual framework. Soc Sci Med 65(7):1442–1457. doi:10.1016/j.socscimed.2007.05.033

Ryan, C. (2013). Language Use in the United States: 2011. American Community Survey Reports (pp. 1–16.). http://www.census.gov/prod/2013pubs/acs-22.pdf. Accessed 5 November 2013

Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, Leong-Grotz K et al (2003) Closing the loop: physician communication with diabetic patients who have low health literacy. Arch of Intern Med 163(1):83–90. doi:10.1001/archinte.163.1.83

Siegel R, Naishadham D, Jemal A (2013) Cancer statistics, 2013. CA: CA Cancer J Clin 63(1):11–30. doi:10.3322/caac.21166

Sudore RL, Schillinger D (2009) Interventions to improve care for patients with limited health literacy. J Clin Outcomes Manag 16(1):20–29, NIHMSID: NIHMS88660

Sussner KM, Jandorf L, Thompson HS, Valdimarsdottir HB (2010) Interest and beliefs about BRCA genetic counseling among at-risk Latinas in New York City. J Genet Couns 19(3):255–268. doi:10.1007/s10897-010-9282-4

Thomas SB, Fine MJ, Ibrahim SA (2004) Health disparities: the importance of culture and health communication. Am J Public Health 94(12):2050–2050. doi:10.2105/AJPH.94.12.2050

U.S. Department of Health and Human Services. (2000). Healthy people 2010. Chapter 11, Health Communication. In: Healthy People 2010. Government Printing Office

US Census Bureau. (2000). Population by race alone, race in combination only, race alone or in combination, and Hispanic or Latino origin, for the United States: 2000. Population by Race and Hispanic or Latino Origin for the United States: 1990 and 2000 (PHC-T-1). http://www.census.gov/population/www/cen2000/briefs/phc-t1/index.html. Accessed 13 January 2014

US Census Bureau. (2013, December 17). USA QuickFacts from the US Census Bureau. http://quickfacts.census.gov/qfd/states/00000.html. Accessed 1 January 2014

Vadaparampil ST, Wideroff L, Breen N, Trapido E (2006) The Impact of acculturation on awareness of genetic testing for increased cancer risk among hispanics in the year 2000 national health interview survey. Cancer Epidem Biomar 15(4):618–623. doi:10.1158/1055-9965.EPI-05-0378

Vanneste R, Chiu SM, Russell L, Fitzpatrick J (2013) Effects of second language usage on genetic counseling training and supervision. J Genet Couns 22(1):58–75. doi:10.1007/s10897-012-9509-7

Warren NS (2011) Introduction to the special issue: toward diversity and cultural competence in genetic counseling. J Genet Couns 20(6):543–546. doi:10.1007/s10897-011-9408-3

Washington HA (2007) Medical apartheid: the dark history of the medical experimentation on black americans from colonial times to the present. Doubleday, New York

Weitzel JN, Lagos V, Blazer KR, Nelson R, Ricker C, Herzog J, McGuire C et al (2005) Prevalence of BRCA mutations and founder effect in high-risk hispanic families. Cancer Epidem Biomar 14(7):1666–1671. doi:10.1158/1055-9965.EPI-05-0072

Weitzel JN, Clague J, Martir-Negron A, Ogaz R, Herzog J, Ricker C, Jungbluth C et al (2013) Prevalence and type of BRCA mutations in Hispanics undergoing genetic cancer risk assessment in the southwestern united states: a report from the clinical cancer genetics community research network. J Clin Oncol 31(2):210–216. doi:10.1200/JCO.2011.41.0027