Title

Cancer Counseling of Low-Income Limited English Proficient Latina Women Using Medical Interpreters: Implications for Shared Decision-Making

Journal

Journal of Genetic Counseling, 27(1)

ISSN

1059-7700

Authors

Kamara, Daniella
Weil, Jon
Youngblom, Janey
et al.

Publication Date

2018-02-01

DOI

10.1007/s10897-017-0132-5

Peer reviewed

J Genet Counsel (2018) 27:155–168
DOI 10.1007/s10897-017-0132-5

ORIGINAL RESEARCH

Cancer Counseling of Low-Income Limited English Proficient Latina Women Using Medical Interpreters: Implications for Shared Decision-Making

Daniella Kamara[1] · **Jon Weil**[2] · **Janey Youngblom**[2] · **Claudia Guerra**[3] · **Galen Joseph**[4]

Received: 12 January 2017 / Accepted: 16 July 2017 / Published online: 9 August 2017

Abstract In cancer genetic counseling (CGC), communication across language and culture challenges the model of practice based on shared decision-making. To date, little research has examined the decision-making process of low-income, limited English proficiency (LEP) patients in CGC. This study identified communication patterns in CGC sessions with this population and assessed how these patterns facilitate or inhibit the decision-making process during the sessions. We analyzed 24 audio recordings of CGC sessions conducted in Spanish via telephone interpreters at two public hospitals. Patients were referred for risk of hereditary breast and ovarian cancer; all were offered genetic testing. Audio files were coded by two bilingual English-Spanish researchers and analyzed using conventional content analysis through an iterative process. The 24 sessions included 13 patients, 6 counselors, and 18 interpreters. Qualitative data analyses identified three key domains – Challenges Posed by Hypothetical Explanations, Misinterpretation by the Medical Interpreter, and Communication Facilitators – that reflect communication patterns and their impact on the counselor's ability to facilitate shared decision-making. Overall, we found an absence of patient participation in the decision-making process. Our data suggest that when counseling LEP Latina patients via medical interpreter, prioritizing information with direct utility for the patient and organizing information into short- and long-term goals may reduce information overload and improve comprehension for patient and interpreter. Further research is needed to test the proposed counseling strategies with this population and to assess how applicable our findings are to other populations.

Keywords Cancer genetic counseling · Limited-English proficiency · Shared decision-making · Health communication · Language access · Medical interpreter · Health disparities · Health literacy · Low-income

Introduction

Shared decision-making is the leading model of patient-centered medical practice (Barry and Edgman-Levitan 2012). In cancer genetic counseling (CGC), the patient is asked to make a decision regarding genetic testing. This decision is highly personal and the outcome will guide the counselor's recommendations for risk-reducing interventions and subsequent decisions about the patient's healthcare management. Shared decision-making is "an approach where clinicians and patients share the best available evidence." (Elwyn et al. 2010, p. 971). Patients are encouraged to consider options, communicate their preferences, and help select best course of action for them. It enables the patient to participate fully in the decision without having to assume complete responsibility for processing unfamiliar information (Elwyn et al. 2000; Hunt et al. 2005). Research has shown that shared decision-making can improve patient outcomes such as treatment compliance and satisfaction (Xu et al. 2004). Furthermore, it may be especially

✉ Daniella Kamara
daniella.kamara@cshs.org

[1] Women's Cancer Program, Cedars-Sinai Medical Center, Los Angeles, CA, USA

[2] Department of Biological Sciences and Human Genetics, California State University, Stanislaus, Stanislaus, CA, USA

[3] Department of General Internal Medicine, University of California, San Francisco, San Francisco, CA, USA

[4] Department of Anthropology, History, and Social Medicine, University of California, San Francisco, San Francisco, CA, USA

beneficial for women who have a hereditary cancer predisposition and need to make decisions regarding illness management and prophylactic treatments (Van Roosmalen et al. 2004).

Successful shared decision-making requires effective communication, where both parties share a mutual understanding of content and intention. Limited English proficiency (LEP), defined as any person age 5 and older who reported speaking English less than "very well" as classified by the U.S. Census Bureau, is a significant communication barrier and contributes to disparities in health outcomes (Fernandez et al. 2011; Healthy People 2020; Karliner et al. 2007; Karliner et al. 2012). Approximately 17% of the U.S. population is Hispanic/Latino and over 21% reported speaking a language other than English at home, of which 13% were Spanish-speakers (U.S. Census Bureau 2015). In California where our study was conducted, 39% of the population identified as Hispanic or Latino (U.S. Census Bureau 2015) and 43% spoke a language other than English, with Spanish spoken by 28% (MLA Language Map 2010). Furthermore, LEP patients are more likely to have limited health literacy (LHL), and the combination of LHL and LEP are synergistic with respect to patients' experiences of communication challenges (Kutner et al. 2006; Rudd 2007; Sudore et al. 2009). As such, the increasing linguistic diversity in the U.S., and the accompanying cultural diversity, present a challenge for genetic counselors (GCs) (Lewis 2002; Ota Wang 2001; Weil and Mittman 1993). The possibility of genetic counseling services that may lead to inappropriate screening or treatment due to language barriers is a serious concern (Bhogal and Brunger 2010; Joseph and Guerra 2015).

Professional medical interpreters can improve communication between providers and LEP patients (Jacobs et al. 2001; Karliner et al. 2007). However, despite legal requirements to provide interpreters for LEP patients (Chen et al. 2007), access is limited by deficits in availability of adequately trained professional interpreters (Flores 2005; Karliner et al. 2016). Effective interpretation requires language proficiency and mastery of medical terminology in both languages, as well as memory skills, ability to negotiate a three-way conversation, and basic knowledge of cultural customs that can influence health communication (Quan and Lynch 2010). The oncology setting, with its complex information and potential for information overload, can be particularly challenging for interpreters (Butow et al. 2012; Perez et al. 2016; Silva et al. 2016). In prenatal genetic counseling, research has shown that misinterpretation limited comprehension and inhibited development of a trusting relationship (Browner et al. 2003). Browner and colleagues also found that group dynamics that sometimes develop among GC, client, and interpreter could negatively impact communication.

Due to increasing demand for interpreter services, health systems are increasingly turning to remote interpreters, available by telephone or video conferencing (Locatis et al. 2010; Nápoles et al. 2010; Nápoles et al. 2015). Given that remote interpretation is a relatively recent phenomenon, research on medical interpretation has only recently begun to compare these different modes of interpretation (Locatis et al. 2010; Price et al. 2012). While some research indicates that remote video interpretation is virtually equivalent in quality to in-person interpretation when measured by the number accurate versus inaccurate interpretations (Nápoles et al. 2010; Nápoles et al. 2015), additional research is needed to assess how telephone interpretation, which does not allow for non-verbal communication, impacts communication effectiveness and health outcomes.

Prenatal and cancer genetic counseling have been the subjects of decision-making research; however, studies in the cancer setting have involved predominately educated, middle-class, white women (Etchegary et al. 2009; Frost et al. 2004; Hesse-Biber and An 2016; Underhill and Crotser 2014). Studies of prenatal decision-making among low-income Latina women identified important differences from white middle class women. For example, low-income Latina women tended to be more accustomed to receiving prescriptive medical advice from health care providers; therefore, the shared decision-making approach taken by the GC was often misconstrued as a sign that the intervention was not truly needed or left the patient confused about the nature of the appointment (Browner and Preloran 1999; Browner et al. 2003; Seth et al. 2011; Sheets et al. 2012).

The purpose of the present study was to: (1) identify communication patterns in CGC sessions utilizing medical interpreters via telephone with low-income LEP Latina women, and (2) assess how the communication patterns facilitate or inhibit the decision-making process during the sessions.

Methods

Participants and Procedures

For this study, we analyzed a subset of CGC session audio recordings collected as part of a larger study in which 170 CGC sessions conducted in English, Spanish and Chinese dialects were observed and audio recorded (Joseph et al. 2017). Both the larger study and the sub-study reported here received approvals for all study procedures from the appropriate IRBs.

The larger study was conducted over a period of 30 months (2012–2015) and used multiple inductive methods, including standard ethnographic techniques to conduct systematic observations, audio-recording of GC sessions, and stimulated recall interviews with observed patients (Bernard 2003; Joseph et al. 2017; Lyle 2003). The study was conducted at two public county hospitals in large metropolitan areas of California. These "safety net" health care systems are publicly

owned, and nearly all patients they serve are covered by Medicaid, Medicare, or are uninsured. Masters-level licensed GCs provided genetic counseling and testing, which was available to patients free of charge through MediCal (California's Medicaid program), Medicare, county health programs, laboratory hardship programs, and foundation support. We obtained verbal consent from counselors and patients to observe and audio record the CGC sessions, which were conducted in-person, with interpreters providing their service by phone. Interpreters included some who were hospital employees and some who worked for a contracted interpreter services company. All patients who had appointments when a language concordant researcher was available were eligible for inclusion in the study.

For the present study, we analyzed a subset of audio recordings based on the following eligibility criteria: Spanish speaking female patients age 21 or older of any race or ethnicity; referred to genetic counseling based on a personal or family history of cancer; offered genetic testing for hereditary cancer syndromes; use of a professional medical interpreter via telephone to conduct the session. Three types of sessions were observed: "pre-test" educational sessions that sometimes included consent for genetic testing and blood draw/saliva sample collection; "pre-test 2" sessions that included review of information conveyed in the initial pretest session, consent for testing, and sample collection; and "result" disclosure sessions.

Data Analysis

The audio recordings were coded and analyzed using Dedoose qualitative data analysis software (Version 7.6.6) Dedoose (2016). The primary and secondary coders are bilingual English-Spanish speakers (DK, CG), both of whom listened to the recordings multiple times prior to and during the coding process. We used conventional content analysis (Hsieh and Shannon 2005) in an iterative process that involved examining and re-examining the facts and meanings contained in the data, ultimately developing more refined ideas about domains of interest. The initial list of codes was derived from the codebook created for the larger study and was modified iteratively to fit themes arising from the content analysis. Initially, five sessions were coded and analyzed separately by each coder, who then met to reconcile differences and establish a codebook. We repeated this process with the remaining audio files using the established codebook. After salient dimensions of culture, health literacy, and language in GC-patient communication were identified, the primary coder (DK) reviewed relevant codes and sub-coded the data. Review of excerpts and recoding continued throughout the writing process as review of the data evoked new insights and perspectives.

While performing the data analysis the first author spent four days as a GC Intern at one of the hospitals included in the study. In that capacity, she observed counseling sessions and provided CGC for English and Spanish speaking patients. Although bilingual, she was not a certified bilingual provider at the hospital and thus used a telephone interpreter with Spanish speaking patients. Through this ethnographic approach, which involved direct observation and clinical practice, she encountered first-hand many of the challenges discussed in the themes below. This experience enhanced her understanding of the clinical context and her analysis of the data, which she had not collected herself (Atkinson and Hammersley 1994; Denzin and Lincoln 1998; Johnson and Sackett 1998).

Results

Participants

Twenty-four audio-recorded sessions (10 pre-test, 7 pre-test 2, and 7 result disclosure) involving 13 patients, four GCs and two GC interns were included in the study (Table 1). We estimate that 18 interpreters were involved in the 24 sessions. This estimate is based on voice recognition because

Table 1 Cancer genetic counseling sessions

Patient ID	Session #	Appointment type	Counselor ID*	Hospital site
6	1	Pre-test 2	3	1
6	2	Result disclosure	3	
13	3	Pre-test	7	1
13	4	Pre-test 2	Intern 1	
13	5	Result disclosure	7	
14	6	Pre-test 2	7	1
14	7	Result disclosure	3	
15	8	Pre-test	7	1
15	9	Pre-test 2	7	
15	10	Result disclosure	7	
17	11	Pre-test 2	7	1
17	12	Result disclosure	7	
18	13	Pre-test	3	1
18	14	Pre-test 2	3	
18	15	Result disclosure	3	
19	16	Pre-test	2	2
20	17	Pre-test	Intern 2	1
20	18	Pre-test 2	7	
20	19	Result disclosure	7	
22	20	Pre-test	2	2
23	21	Pre-test	7	1
24	22	Pre-test	7	1
29	23	Pre-test	1	2
65	24	Pre-test	1	2

*Counselor ID numbers are taken from the larger study (Joseph et al. 2017)

interpreters did not consistently provide their names at the start of each session. The average length of the pre-test session was 42 min and they ranged in length from 16 to 69 min. The average length of the results session was 21 min and they ranged in length from 10 to 54 min. Of the audio-recorded sessions, 12 were conducted by GC7, six by GC3, two each by GC2 and GC1, and each one by each GC intern.

Patients were immigrants from Mexico, Nicaragua, and El Salvador, aged 26–49, and more than half had an education level of less than high school (Table 2). Six of the patients had a diagnosis of DCIS/breast cancer and seven were unaffected. All 13 patients accepted the offer of genetic testing.

Qualitative Analysis

Qualitative data analyses identified three key domains that reflect communication patterns and their impact on the counselor's ability to facilitate shared decision-making in the session: (1) Challenges Posed by Hypothetical Explanations, (2) Misinterpretation by the Medical Interpreter, and (3) Communication Facilitators. Data from all genetic counselors and interns provided support for this analysis. The excerpts presented in Results were chosen because they illustrate a given issue or communication pattern succinctly and clearly.

Domain One: Challenges Posed by Hypothetical Explanations

During pre-test appointments, GCs often tried to guide the patients' decision-making by using hypothetical scenarios to explain possible test results and informative versus uninformative results. These "if…then" scenarios were typically lengthy and required abstract, future-oriented thinking on the part of the patient. Our analyses suggest that they did not effectively facilitate the patient's decision-making about genetic testing. Furthermore, we found that the use of hypothetical explanations often inhibited patient engagement and dynamic discussion between GC and patient, as shown in the following excerpt.

> **GC:** The best way for us to figure out if it's genetic is, would have been to actually test your mom and look at her two BRCA genes (Interpreter)[1] and that would tell us: does she have a change in those genes that had contributed to her breast cancer? But because she is not alive that's not a test we can obviously do. (Interpreter) But we can test you. It is not, may not give us, umm, as much helpful information, and so I am going to talk a little bit about that. (Interpreter) So what we will do is we will go ahead and look at your BRCA1 and BRCA2 genes. (Interpreter) If we see a mutation then we would just make the assumption that you had inherited that mutation from your mother, (Interpreter) and then that would really answer the question. It would not only explain why your mother got cancer so young, but it would also give us important information about your risk for cancer. (Interpreter) And then because we would know you are at a higher risk for cancer we would talk about the best ways we would be monitoring you and taking care of you to help reduce your risk of getting cancer. (Interpreter) So do you have any questions about any of that so far? (Interpreter)
> **Patient:** No, everything is fine thank you. (Interpreter) [GC 7; unaffected Patient 20; Session 18]

The GC's explanation of an informative positive test result, which incorporated the hypothetical scenario of testing the patient's deceased mother and the conclusions that could be drawn from it, were met with a minimal response from the patient. As the explanation continued, the counselor provided additional information using hypothetical scenarios to explain the possible meanings of a negative genetic test result. Overall, this patient was not responsive throughout the session, appeared to understand little of what was discussed, and seemed pre-occupied by her physical symptoms of breast pain and her fear of cancer. In addition, the counselor did not effectively elicit input from the patient, which she could have used to assess the patient's understanding and facilitate shared decision-making.

The need to discuss the limitations of genetic testing was particularly relevant in this population, which included unaffected immigrant patients whose affected, genetically informative, relatives lived in another country where genetic testing was unavailable or from which no medical records could be obtained. GCs used the patient's family history to contextualize the patient's negative test result and to explain recommendations for increased surveillance, as in the following excerpt from the results session with the same patient as the preceding excerpt.

> **GC:** So, if we go back to your family history and we look at the—the main history that we are worried about is your mother's very young age of breast cancer. (Interpreter) And we talked about, way back when, when you had the testing, about how it's always better for us to test somebody who has had cancer instead of someone who hasn't, (Interpreter) which we couldn't do in your family because your mother is no longer with us. (Interpreter) But if we had been able to test your mother and do this same test, and we had seen that there was a mutation, then we would know better what this means for you. (Interpreter) Because if you look at my little scribbles from last time, if your mother carried this

[1] "(Interpreter)" indicates when the GC and/or patient paused to allow the interpreter to translate. The transcriptions do not include the interpreter's speech except when the interpreter's translation is relevant.

Table 2 Patient demographics

Patient	Country of origin	Years in US	Age	Marital status	Occupation	Education	Cancer status
6	Mexico	23	45	Married	Caregiver	Less than HS	DCIS
13	Nicaragua	16	40	Legally separated or divorced	Babysitter	College or higher	Unaffected
14	*Unknown**	*Unknown*	43	*Unknown*	*Unknown*	*Unknown*	Unaffected
15	El Salvador	13	45	Married	Fast Food Cook	Less than HS	Unaffected
17	Mexico	21	42	Married	Cook	Less than HS	Unaffected
18	El Salvador	*Unknown*	*Unknown*	*Unknown*	*Unknown*	*Unknown*	Breast Cancer
19	Mexico	22	51	Legally separated or divorced	Caregiver	Less than HS	Breast Cancer
20	Nicaraguan	5	26	Long-term partner	Bartender	Less than HS	Unaffected
22	Mexico	10	32	Married	Not working/CA treatment	Less than HS	Breast Cancer
23	El Salvador	13	42	Married	Disability	College or higher	Breast Cancer
24	Mexico	*Unknown*	43	*Unknown*	*Unknown*	*Unknown*	Unaffected
29	Mexico	*Unknown*	44	Long-term partner	Cleaning service	*Unknown*	Unaffected
65	Mexico	30	49	Married	Cleaning service	Less than HS	Breast Cancer

*Demographics were collected as part of an interview process conducted with selected patients for the larger study. Not all patients participated in an interview and therefore demographic data are not complete. Some additional demographic data were extracted from the audio recordings

mutation, there would be a fifty-fifty chance whether you inherited that from her so, but, we couldn't do that. So we are left with just trying to interpret your test result. (Interpreter) If you had tested positive, if you had a mutation, which fortunately you didn't, then we would know that your mom had one and that you inherited it from her, (Interpreter) but you have this copy that doesn't have any mutation on it. (Interpreter) That could be because your mother did have a mutation and you just, fortunately, did not inherit it. (Interpreter) But the part we don't know, we don't know if maybe her cancer wasn't genetic at all, or maybe it was due to some other genetic cause. (Interpreter) So what that really means is that although it's good that this is negative, we still want to be a little cautious as we follow you going forward. (Interpreter) This, these genes are the most common genes that have mutations or changes when we have hereditary breast cancer, so the test is quite reassuring. (Interpreter) So it's not that the test is completely uninformative, it is good news, but there is still a small chance that we didn't test for the right thing, and we wouldn't know that. (Interpreter) So there is no way for us to know for sure, since we can't test your mother. (Interpreter) Does that make sense? (Interpreter)

Patient: Yes. (Interpreter)

GC: Kind of? Or, it does? I know it can be a little confusing. (Interpreter)

Patient: [giggling] No, everything is fine. (Interpreter) [GC 7; unaffected Patient 20; Session 19]

From the pre-test session, the GC knew that no relatives were available for testing; therefore, the purpose of this extensive explanation, employing multiple hypotheticals, was to ensure that the patient understood the limited nature of her result and the reason for additional surveillance. The counselor's yes/no question and the patient's response did not give the counselor any means by which to assess the patient's comprehension or potential psychosocial concerns pertaining to the information provided. A one-sided conversation resulted, inhibiting development of an interactive exchange between the GC and the patient.

Information about result limitations and subsequent management outcomes provided in the pre-test session was often repeated in the result disclosure session. However, once the test result was known, it was presented in the context of the patient's personal and/or family history, thus avoiding lengthy explanations of other possible scenarios or results. Tailoring the discussion to the patient's circumstance and providing focused information and recommendations, rather than multiple hypothetical scenarios, in some cases contributed to the development of an interactive rapport between GC and patient.

In the following example from a results session, the patient voiced lingering confusion from the pre-test hypothetical discussion of possible test results regarding a VUS ("something in the middle"). However, the fact that the genetic counselor could now provide a specific result provided a means to clarify the situation for the patient.

GC: So, umm, the test, this big green umm minus sign so that means negative. So everything they looked at was normal, (Interpreter) and down here are all the, remember we talked about the fact that this is a panel of several cancer genes. (Interpreter) And so the ones we think most about are the breast cancer genes, BRCA1 and 2, (Interpreter) but these genes and all these other genes, all these letters and numbers, are different genes and they all have the usual, normal sequence that we

would expect to see. (Interpreter) So no mutations were detected. (Interpreter) Do you have any questions about the test result? (Interpreter)
Patient: [to interpreter] Yes, I have a question because she told me that many times these tests either come back negative or come back positive but there is always something middle. What is the possibility, the chance that I have from that? (Interpreter)
GC: Right, sometimes we get a test result that we don't exactly know what it means. But we didn't find that, yours was completely negative. (Interpreter)
Patient: Oh, okay. (Interpreter)
GC: Okay, so it was completely negative. (Interpreter)
Patient: Okay. (Interpreter) [GC 7; unaffected Patient 13; Session 3]

In this case, the patient's question provided the GC the opportunity to clarify the confusion and reassure the patient that the result was completely negative. However, most participants in this study did not vocalize questions or ask for clarification of results and information. Therefore, GCs could not provide this level of reassurance and clarification in most sessions.

We also found that the abstract nature of hypothetical explanations was challenging for medical interpreters to understand and translate. Hypotheticals typically required the use of complex grammatical constructions as well as an understanding of genetic counseling goals in communicating the information. The multiple "if…then" statements, involving different results, relatives, and management outcomes as in the previous case, could be complicated and challenging to interpret accurately and sometimes resulted in misinterpretation. Occasionally interpreters voiced their confusion and asked for clarification, as shown in this excerpt.

GC: So, umm, one possibility is that maybe someone somewhere in your mom's family there is some type of genetic mutation that caused all of those people to get cancer at young ages. (Interpreter) But maybe whatever is causing that pattern of cancers in your mom's family—it just wasn't something that your mom [inherited] and not something that you [inherited either].
Interpreter: [to patient] Okay… (Interpreter) [To GC] I'm sorry can you repeat the last thing you said?
GC: [to interpreter] Umm, yeah, so…it's possible that there is some type of hereditary predisposition in her mom's family that her mom just didn't inherit. (Interpreter) [GC 3; unaffected Patient 14; Session 7]

In this case, the interpreter solicited clarification and the GC addressed the interpreter directly in her response (i.e. she spoke to the interpreter referring to the patient as the third party). In other cases, the interpreter skipped or truncated the hypothetical explanation and misinterpretations resulted. Outlining a hypothetical testing scenario to explain the limitations of genetic testing introduced complexity to the discussion, and could thereby increase the potential for interpretation errors, especially if the interpreter did not solicit clarification from the counselor, which is an additional challenge within the session, as discussed further below.

Domain Two: Misinterpretation by the Medical Interpreter

Various factors led to misinterpretations including misunderstanding of terminology, concepts, hypotheticals, and/or the GC's intent as well as mishearing and/or human error, which is common in human communication. Due to the language barrier, neither the GC nor the patient could identify misinterpretations when they occurred. Therefore, many were left uncorrected and led to misconceptions on the part of the GC and/or the patient.

Misunderstanding of genetic concepts, such as hereditary cancer syndromes, was a common cause of misinterpretation leading to incorrect information conveyed to the patient. In the following example, as part of the GC's education about Hereditary Breast and Ovarian Cancer Syndrome (HBOC), the GC described associated risks beyond breast cancer.

GC: So when umm when people have mutations in these genes it can cause, it can increase the risk of cancers beyond just breast cancer. (Interpreter)
Interpreter: [to patient] Miss she says, when there are mutations in these genes it can also cause other, it can increase the risk that it can cause different types of cancer, not only breast cancer.
GC: Next most common cancer is ovarian, and there is a somewhat increased risk for skin cancers.
Interpreter: [to patient] So she says, the other most common type that would be on the list would be cancer of the ovaries, and if one has been exposed to the sun it places—increases the risk for skin cancer. [GC 7; Session 11]

Here, the interpreter conveyed correct information to the patient: sun exposure can increase the risk of skin cancer. However, she failed to communicate that the increased cancer risks associated with HBOC include skin cancer. The misinterpretation was left uncorrected. Thus, one can assume that the patient left the session with inaccurate information about the role of the genetic mutation and associated risk of melanoma.

The following excerpt illustrates the impact of misinterpretation on the process of taking a patient's family history, an integral tool used by the GC to develop rapport and make a psychosocial assessment.

GC: Do you know how old your father's parents lived to be?
Interpreter: [to patient] To what age did your parents live?
Patient: They are still alive.
Interpreter: [to GC] They are still alive.
GC: Okay, how old are they? Do you have any idea? (Interpreter)
Patient: [laughs] Truthfully, I don't remember. (Interpreter)
GC: Okay, probably though uhh maybe in their 80's or 90's?
INTERPRETER DOES NOT TRANSLATE GC's QUESTION
Patient: But above 50, above 50, between 50 and 60. (Interpreter)
GC: Oh, is this uhh I was asking about your father's parents, is that who you are talking about?
Interpreter: [to patient] I'm referring to [to GC] this is the interpreter; do you mean her grandparents?
GC: [to interpreter] Correct.
Interpreter: [to patient]: We are asking about your grandparents.
Patient: [pauses] Oh, if they are alive?
Interpreter: [to patient] Yes.
Patient: Oh, yes, well the parents of my mother are alive. (Interpreter) [GC 3; affected Patient 18; Session 14]

The interpreter's translation of "father's parents" as "parents" led to a confusing exchange. Unlike most misinterpretations, in this case the confusion became apparent to the GC who then clarified the misunderstanding. The fact that a misinterpretation had occurred was never addressed directly. Although the miscommunication was caught and clarified, confusion on the part of the patient seemed to linger as the discussion of her family history continued.

GC: Okay, okay. And on your father's side do you know what they passed away from? (Interpreter)
Patient: Well, my grandfather I don't know what he died from. But my dear grandmother, she developed something like ulcers on her body because she had something here, a scar, that's what I remember.
Interpreter: [to GC] On my grandmother's side, my grandmother I don't know what she died of. But my grandfather, he had some ulcers on his body, I really don't know what they were from.
GC: Hmm, okay.
Patient: They were like ulcers, and from these ulcers she lost her foot, they did an amputation. What else? Yes, but more importantly she lost her foot. But they were these ulcers that appeared but never...but those were other times, it was just what the doctor said, and then suddenly she died.
Interpreter: [to GC] These are little ulcers that due to these ulcers he had his foot amputated. And you know really back then it was according to what the doctor said we really don't know what happened or what it was. [GC 3; affected Patient 18; Session 14]

In this interaction, the misinterpretation affected the GC's understanding of the patient's family history and narrative, precluding an opportunity to better understand and address a difficult time in the patient's life, build rapport, and establish a more open line of communication with the patient.

Communication barriers were often created by misinterpretations due to misunderstanding the counselor's underlying goals and purpose of specific statements or questions. The following excerpt illustrates how such misinterpretations could inhibit rapport, communication, and psychosocial assessment from the beginning of a session:

GC: Do you um, know why your doctor wanted you to come in and see me? (Interpreter)
Patient: Well, yes. They told me, well I want the genetic test, and they told me that I had to, that they would provide me counseling about what the genetic test entails.
Interpreter: So I said I wanted to have a, see a genetics counselor and I think that's why they referred me here.
GC: Okay, okay to talk about family history of cancer. (Interpreter) [GC 7; affected Patient 23; Session 21]

The patient stated that she wanted the genetic test, indicating that she had some prior knowledge or familiarity with it, and that she had made a decision about testing. The interpreter's omission of this crucial information about the patient's intention led the GC to approach the decision-making process as she would a patient who is undecided or does not have prior knowledge of genetic testing, which is true of many patients in this setting. Without this critical information, she could not explore the patient's knowledge and perceptions of genetic testing, or use that information to facilitate a shared decision-making process.

Domain three: Communication Facilitators

We also identified specific strategies counselors used to elicit meaningful responses from the patient and engage them in a dynamic discussion. Given that testing may be recommended but is not mandatory, GCs typically asked patients to make a decision about testing. In the limited cases in which the GC explicitly stated both options, to test or not to test, a dynamic discussion developed. In the following example, the counselor opened the opportunity for the patient to express her concerns,

which allowed the counselor to address them as she guided a discussion of the pros and cons of testing for this patient.

GC: Not everybody wants the testing, not everyone wants to know if they have that risk factor, so I am going to talk about some of the pros and cons of the testing. (Interpreter)
Patient: Yes, in reality I did not want it because I said, what would happen if it comes out the gene, that I have the gene? I would be worried, and I didn't want it. Because they were calling me, I said okay I will go, but I am a little undecided. (Interpreter)
GC: But you're, you're not so sure that this is something that you want to do. I kind of sense that from you. (Interpreter)
Patient: [hesitates] Umm I know that this is something I have to do, uh but internally I don't really want to but well [let's proceed] if it's for my benefit. (Interpreter)
[GC 7; unaffected Patient 24; Session 22]

The counselor normalized the patient's concerns about testing by mentioning that not everyone wants it. Once the patient expressed doubts, the counselor could acknowledge the concern, and subsequently review in detail the benefits of genetic testing, as well as the reasons some people choose not to have testing or choose to wait until a later time. By engaging the patient in this manner, the GC could personalize the information to fit the patient's needs and circumstances, rather than present it in an abstract or generic manner.

In the following excerpt, the counselor reviewed the possible test results with a patient who had returned for more comprehensive testing after a negative BRCA1/2 test. The counselor defined technical terms as she used them, kept her explanations concise and outlined each test result without the, potentially confusing, hypothetical explanations discussed above. Importantly, the counselor stated that details would be discussed once a specific result was identified, thereby anticipating the patient's potential anxieties and concerns, and reassuring the patient that all relevant information would be disclosed once it was available.

GC: Now the other thing that I need you to know is when we do this test, you know last time your results were clearly negative. (Interpreter) So negative means we didn't find any mutations or spelling mistakes in these genes. (Interpreter)
Patient: Okay.
GC: When we do this test, obviously, we can also find a positive test result which means we did find a mutation that we know is associated with high risks for cancer. (Interpreter) And so for these people that's when we begin to recommend that they have more screening, and there are a number of things that we would talk about at that point when somebody has a positive result like that. (Interpreter)
Patient: Okay.
GC: There is also a third possible answer we can get, (Interpreter) and we call these answers variants. (Interpreter) And what that means is that the gene is spelled in a different way than we expect but we don't know for sure if that is associated with higher risks for cancer or not. (Interpreter) Many times we find that these variants are different ways to spell that gene and it doesn't cause any problems for the way the gene works. (Interpreter) But sometimes those variants, we can later find out that they are associated with higher risks for cancer and that information just comes over time as we learn more.
Patient: Okay.
GC: If somebody has a variant we generally don't recommend any increased screening at that point, we really look at the family history and personal history of cancer to guide those screening recommendations. (Interpreter)
Patient: Okay.
GC: Any questions about that? (Interpreter)
Patient: No, I think I understood very well. (Interpreter)
[GC 1; affected Patient 65; Session 24]

After this explanation, the patient thanked the GC stating that she had not received any of this information in her prior testing experience. The patient's comprehension allowed for a dynamic discussion to evolve. Throughout the session, the patient was actively engaged and asked informed questions that clearly demonstrated her understanding.

At times, the interpreter went beyond his or her role as a conduit for the counselor's words. This expanded role could enhance communication and limit errors. The following excerpt illustrates the interpreter's interrelated role as a cultural bridge between patient and GC, clarifying meaning and intent of both parties.

GC: It's a very expensive test. (Interpreter) Um and so we can, you know, we can discuss it but we get many of our patients qualified for this free testing as long as we submit the correct paperwork. (Interpreter) What are you thinking? Do you have some questions for me?
Interpreter: What happened? Do you have a question for us?
Patient: Yes, when you say papers to what are you referring?
Interpreter: [to patient] No [to GC 1] Yes, yeah, because I used the word papers and papers mean documents.
GC: Right okay, sorry. So, I need you to bring the letter from your employer stating what your monthly income is and then I will have an additional form, two forms,

that I will need you to sign. (Interpreter) [GC 1; unaffected Patient 29; Session 23]

Patients in this underserved, immigrant population are often undocumented. In this case the translation of "papers" may have alarmed the patient because the term is often used to indicate citizenship or legal residency documentation rather than the proof of income the counselor needed. The interpreter was able to clarify the meaning for both the patient and the counselor.

In the following session, the interpreter was unsure of his word choice. Instead of using his own judgment, he checked with the GC to verify that a word change would not compromise the content of the information.

GC: So, and we have that negative family history and we have these negative results. It really could just be that the cancer that you had is just sporadic, just by chance.
Interpreter: [to patient] Okay, taking into account the result of this test and the family history it's [to GC] I'm sorry could I use the word random?
GC: [to interpreter] Uh sure, sure.
Interpreter: [to patient] So, it could be something random, in other words something that just happened. [GC 3; Session 2]

This example illustrates a common problem during interpreted sessions: the GC's inability to ensure correct translation of information and technical terminology without the active participation of the interpreter. It also illustrates a dilemma for healthcare interpreters, who typically are not trained in genetics, regarding how to accurately translate the GC's nuanced words. The interpreter's request for clarification allowed both the interpreter and the GC to verify that the information was conveyed in the manner intended.

Discussion

The ideal GC-patient interaction is one where the GC and patient establish rapport that allows for a two-way discussion in which both parties share a mutual understanding of content and intention (Elwyn et al. 2000). The presence of a medical interpreter creates a three-way conversation, altering the dynamic between the GC and patient. Our analysis of audio recordings of CGC sessions with low-income Latina women with the assistance of professional medical interpreters via telephone identified communication patterns that inhibit and facilitate the kind of dynamic communication needed to successfully achieve shared decision-making, a major goal of genetic counseling.

GCs regularly provided information to patients in pre-test sessions about the range of possible results and the limitations of genetic testing. We found that patients often did not correctly understand this information (also see Joseph et al. 2017). The counselors' use of hypothetical scenarios to explain the possible results and limitations of genetic testing often inhibited effective communication with and subsequent decision-making by the patient. The hypothetical discussions also appeared to increase potential for errors by the interpreter, who without broader knowledge of genetics to provide context, struggled to translate the meaning and nuances in a way that accurately reflected the intended message.

Discussing potential test results and the limitations of testing is consistent with standard practice (Lobb et al. 2001; Prucka et al. 2008). Genetic testing laboratories such as Myriad, Ambry, and Invitae also include this information in their testing consent forms. Stalmeier et al. (1999) found that engaging in these discussions with healthy women with a family history of breast cancer referred to a hospital in the Netherlands increased adherence and improved overall outcomes. However, in our study the complex sentences involving many "if…then" statements challenged interpreters and led to many misinterpretations. In addition, patients were confused about how to use this information, and often did not seem to comprehend the information at all.

Hypothetical explanations involve abstract future-oriented concepts. Seven of the 13 patients were unaffected (did not have cancer), and were referred for GC based on family history. These patients may have had a more challenging time understanding the utility of the appointment and the information provided since it was not immediately applicable to their circumstances. Consistent with this interpretation, a study involving Latino community members found that information needs to be personally relevant to be cognitively processed (Kinney et al. 2010). Other factors also could have contributed to the limited patient responses observed in these cases. For example, patients with limited English proficiency (LEP), Latino patients, and those on Medicaid—all characteristics of our study population—are more likely to have limited health literacy (LHL), and individuals with LHL are less likely to actively participate in health care decision-making discussions (Martin and Parker 2011). Additionally, individuals from unpredictable environments are generally less focused on predictions and decisions that reach far into the future; instead, such life circumstances support the development of short-term plans (Guss and Robinson 2014). The socioeconomic status and immigrant background of the patient population in the current study suggest that tailoring the decision-making process to focus on short-term decisions might enhance communication and decision-making.

Penchaszadeh (2001) proposes that decision-making based on a future time orientation is less commonly seen in Latinos than among white European Americans. This suggests that the difference in temporal orientation between GC and patient in the analyzed sessions may have further exacerbated the

communication gap during discussions of hypothetical scenarios. In addition, Penchaszadeh found that Latino patients facing increased genetic risk are often unimpressed by the risk figures GCs provide, which can be much lower than some of the perils they are used to facing in life, like poverty, lack of health care, social marginalization, discrimination, deportation, or police violence. Patients' minimal responses to hypothetical scenarios could be due to the lack of relevance given the context of the more immediate concerns and risks in their lives.

Interpreters' misinterpretation of critical information and dialogue often led to miscommunications and misconceptions on the part of the patient and may interfere with the genetic counseling goals of educating and empowering the patient, creating good GC-patient rapport, and fostering a dynamic discussion (Bhogal and Brunger 2010). Prior research involving in-person medical interpreters identified problems such as inaccuracy, inconsistency, and confusion regarding the interpreter's role. These studies also confirmed the importance of nonverbal cues that help build rapport between the patient and the GC (Bhogal and Brunger 2010; Dysart-Gale 2007; Flores et al. 2003). While telephone interpreter services have made interpreters more widely available for LEP patients, our study suggests it may also complicate communication in the absence of specific strategies to replace the nonverbal cues that indicate a misunderstanding or the need for clarification, which may be more readily available when the interpreter is physically present. Additionally, misinterpretations occurred in our study when the interpreter lacked understanding of the GC's goals or the context of the GC's explanation. GCs' use of technical terminology, analogies for technical terms and concepts, and complex explanations such as hypothetical scenarios often led to the transmission of incorrect or incomplete information. In some situations, the interpreter substituted his or her incorrect or partial explanation for that of the GC rather than asking for clarification. Data suggest that there are multiple reasons why an interpreter might not solicit clarification from the counselor, such as the power dynamics between medical providers and interpreters and time constraints of clinical appointments (Lara-Otero et al. 2017).

Our analyses also identified practices that facilitated communication. In most pre-test sessions, testing was presented as a choice but the option not to test was not explicitly stated. On the occasions when both options were explicitly stated, a broader discussion that included patient concerns or doubts about genetic testing became possible. The GC could then address these concerns, answer questions, and correct misconceptions, thereby tailoring the information to fit the patient's needs and circumstances. Explicitly stating the option not to test helped normalize patient hesitation, doubt, and concern for social, cultural, and family norms, which may help the patient communicate more forthrightly. In the cases we observed where the GC stated both options, it appeared to help build rapport, improve comprehension, and open the possibility of a shared decision-making process.

Interpreters had a role in facilitating communication by serving as a cultural bridge between the patient and counselor. When interpreters anticipated and/or explained points of confusion or ambiguity to the GC, clarified questions or information for the patient, or voiced personal questions about content or translation, they allowed for more effective communication between the counselor and patient. Furthermore, this interaction between the counselor and the interpreter fostered a more collaborative atmosphere in which both worked together to achieve the common goal of informing and supporting the patient. Overall this collaboration facilitated communication in the session and reduced the risk for misinterpretation and misunderstanding. Our findings suggest that the interpreters' limited role as a conduit of language does not suffice for effective communication in the GC context, where a broader understanding complex concepts and processing critical implications and outcomes are integral to the decision-making process (Browner et al. 2003; Butow et al. 2012; Flores 2005; Jacobs et al. 2001; Karliner et al. 2007; Lara-Otero et al. 2017).

As previously stated, the first author spent four days as a GC intern in one of the participating hospitals observing and conducting CGC sessions using telephone interpreters. As in the social science method of ethnography (participant-observation) (Schensul et al. 1999), this experience allowed her to experience first-hand the role of a GC in this setting, and to appreciate the challenges that arise in interpreted sessions – from building rapport with a patient without a common language, to assessing comprehension of the patient and the interpreter when explaining complex information. This first-hand experience made the data, which she was not involved in collecting, less abstract, thereby facilitating her understanding of the context and her analysis of the data.

The challenges faced by GCs in this setting cannot be overstated, and tools to navigate the complex communication and provide quality care are essential. The standard practices of pre-test education were developed with and for language concordant discussions between English speaking patients and counselors. Given the increasing number of LEP patients in the US, specific communication strategies for both GCs and interpreters are needed to attend to the counseling challenges such as those identified in our study.

Study Limitations

This study was conducted at two public hospitals in one state with a relatively small sample of counselors and counseling sessions. Furthermore, the majority of the analyzed sessions were conducted by two of the participating GCs (GC 3 and GC 7). Thus, the communication patterns we observed may be influenced by the personalities and counseling styles of the

participating counselors, the culture of the two institutions, patient character and expectations, cultural models of medicine, and other variables (Bhogal and Brunger 2010; Browner et al. 2003; Seth et al. 2011; Penchaszadeh 2001). Nevertheless, the consistency across counselors, counseling sessions and patient responses clearly identify important patterns and issues. In addition, our data are consistent with other research findings (Bhogal and Brunger 2010; Cura 2015; Kinney et al. 2010; Penchaszadeh 2001).

Practice Implications

Some strategies, like those we identified as communication facilitators, (e.g. explicitly stating all choices, defining technical terminology, and involving the interpreter as a cultural bridge, help cultivate a shared environment and can facilitate decision-making) need to be applied more consistently. GCs may continue to implement core skills such as using open-ended questions and teach-back strategies (Brega et al. 2015; Nouri and Rudd 2015; Veach et al. 2007) to engage patients and, more importantly, to assess for misunderstandings and level of comprehension. The various obstacles we observed suggest that GCs need to adapt their approach to counseling LEP patients using interpreters to improve communication and facilitate shared decision-making.

First, given our results regarding the use of hypothetical explanations, we need to find other ways to present possible test results that more clearly demonstrate their applicability and/or utility for the patient. The GC can explicitly state that the patient will be expected to make a choice, and that a central goal of pre-test counseling is to help the patient come to a decision that is consistent with her circumstances and values. The shared decision-making model is generally unfamiliar to this population, which has been found to be more accustomed to a directive model of healthcare (Bhogal and Brunger 2010; Browner et al. 2003; Seth et al. 2011). Patients in our study did not demonstrate understanding of the expectations of the session (i.e. discussing options with the provider and making a decision regarding testing), and counselors did not make those expectations explicit (Joseph et al. 2017). Thus, orienting the patient to shared decision-making (i.e. what it is and how the GC expects to interact with the patient), as well as the overall differences between genetic counseling and a standard medical appointment (i.e. discussion, not a physical exam) could potentially improve the communication.

Second, GCs should consider the take-home messages of the information they provide. What is essential for the patient to understand at any given point in the process? Categorizing the relevant information into short-term and long-terms communication goals could help GCs determine the point at which specific information would be most useful for the patient, and could help the patient understand how to use the information in the present and in the future. For example, in a pre-test session, the short-term goals could be: reason for offering genetic testing, information that the genetic test will provide, and that based on the patient's specific result a specific action plan will follow. In contrast, long-term goals in a pre-test session could be the reason genetic testing may be important for the patient and his or her family. Once the patient's result becomes available and specific information about next steps can be provided, new short-term and long-term goals can be established for the result disclosure session. For example, in the short-term, the patient needs to know his or her result and how it affects his or her immediate medical management (e.g. screening recommendations). Long-term goals for results disclosure could include how this result will affect other family members such as siblings and children.

Third, it is important that GCs use with caution technical terms such as "gene," "DNA," or "chromosome" as well as analogies such as "typo" for mutations. Interpreters may be unfamiliar with these terms or have a prior understanding that may differ significantly from that of the GC. If technical terminology is employed, GCs should consider defining each term in the context of the discussion to ensure interpreter as well as patient understanding. Previous studies have found that interpreters express a need for ongoing training in medical terminology to ensure their knowledge is up-to-date and that they can translate the terms accurately (Lara-Otero et al. 2017). Therefore, specific training for interpreters working with GCs to familiarize them with genetic terminology and concepts could prove useful in minimizing misinterpretations in counseling sessions involving medical interpreters (Lara-Otero et al. 2017; Roat et al. 2016).

Finally, this study has important implications for GC training as well. As the need to provide genetic services through medical interpreters grows, GC training programs should incorporate specific training into their curriculum on effective communication and session management using in-person interpreters as well as remote interpreters via telephone or video.

Research Recommendations

Analyses from the larger study, *Translating Cancer Genetics to the Safety Net Setting,* which included additional patient populations and genetic counselors, as well as interviews with observed patients, counselors and interpreters, shed further light on our results (Cheng et al. 2017; Joseph et al. 2017; Lara-Otero et al. 2017). The utility of the findings presented here and those of the larger study would be strengthened by further research on specific communication strategies that might facilitate shared decision-making with limited English proficiency patients. Ideally, such research would design a communication strategy based on the clinical considerations outlined above (i.e. prioritizing information based on relevancy, categorizing information into short-term and long-term goals, defining technical terminology), and evaluate the effect

of implementing them on the shared decision-making process in genetic counseling sessions utilizing medical interpreters.

Conclusions

Facilitating shared decision-making is an essential part of the GC process that requires effective communication between GC and patient. The communication barriers that arise under cross-cultural counseling circumstances exacerbate the challenges of a typical GC session. This study highlighted various factors that contribute to the challenging dynamic in CGC with low-income LEP Latina women utilizing medical interpreters via telephone. Awareness of factors that inhibit and facilitate the decision-making process can help guide GCs in tailoring information, communication, and session structure appropriately, ultimately improving efficacy of shared decision-making in these sessions. As genetic testing becomes available to a more diverse population, improving communication in GC sessions with low-income LEP Latina women is essential as it can improve quality of care and outcomes for these women and reduce existing health disparities.

Acknowledgements This study was funded by Susan G. Komen for the Cure grant # IIR12221854 (PI Joseph) and was conducted to fulfill degree requirement (Kamara). We are grateful to the patients who participated in this study, and to the genetic counselors who allowed us to observe them in their daily practice. The first author would also like to thank Dr. Amy Lemke, PhD for her expertise and support.

Compliance with Ethical Standards

Funding This study was funded by Susan G Komen for the Cure (Grant number: IIR12221854).

Conflict of Interest Daniella Kamara, Jon Weil, Janey Youngblom, Claudia Guerra, Galen Joseph declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

References

Atkinson, P., & Hammersley, M. (1994). Ethnography and participant observation.

Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine, 366*(9), 780–781.

Bhogal, A. K., & Brunger, F. (2010). Prenatal genetic counseling in cross-cultural medicine: A frame work for family physicians. *Canadian Family Physician, 56*, 993–999.

Brega, A., Barnard, J., Mabachi, N., DeWalt, D., Brach, C., Cifuentes, M., Albright, K., & West, D. (2015). AHRQ health literacy universal precautions toolkit, second edition. (prepared by Colorado health outcomes program, University of Colorado Anschutz Medical Campus under contract no. HHSA290200710008, TO#10.) AHRQ publication no. 15-0023-EF. Rockville: Agency for Healthcare Research and Quality.

Browner, C. H., & Preloran, H. M. (1999). Male partners' role in Latinas' amniocentesis decisions. *Journal of Genetic Counseling, 8*(2), 85–108.

Browner, C., Preloran, H. M., Casado, M. C., Bass, H. N., & Walker, A. P. (2003). Genetic counseling gone awry: Miscommunication between prenatal genetic service providers and Mexican-origin clients. *Social Science & Medicine, 56*(9), 1933–1946. doi:10.1016/S0277-9536(02)00214-9.

Butow, P. N., Lobb, E., Jefford, M., Goldstein, D., Eisenbruch, M., Girgis, A., et al. (2012). A bridge between cultures: Interpreters' perspectives of consultations with migrant oncology patients. *Supportive Care in Cancer, 20*(2), 235–244. doi:10.1007/s00520-010-1046-z.

Chen, A. H., Youdelman, M. K., & Brooks, J. (2007). The legal framework for language access in healthcare settings: Title VI and beyond. *Journal of General Internal Medicine, 22*(2), 362–367.

Cheng, J., Guerra, C., Pasick, R., Schillinger, D., Luce, J., & Joseph G. (2017). *Cancer Genetic Counseling Communication with Low-Income Chinese Immigrants.* Manuscript in preparation.

Cura, J. D. (2015). Respecting autonomous decision making among Filipinos: A re-emphasis in genetic counseling. *Journal of Genetic Counseling, 24*(2), 213–224. doi:10.1007/s10897-015-9823-y.

Dedoose Version 7.6.6, web application for managing, analyzing, and presenting qualitative and mixed method research data (2016). Los Angeles, CA: SocioCultural Research Consultants, LLC (www.dedoose.com).

Denzin, N. K., & Lincoln, Y. S. (1998). The landscape of qualitative research: Theories and issues.

Dysart-Gale, D. (2007). Clinicians and medical interpreters: negotiating culturally appropriate care for patients with limited English ability. *Family & community health, 30*(3), 237–246.

Elwyn, G., Gray, J., & Clarke, A. (2000). Shared decision making and non-directiveness in genetic counseling. *Journal of Medical Genetics, 2*(37), 135–138. doi:10.1136/jmg.37.2.135.

Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *BMJ (Clinical research ed.), 341*, c5146–c5146.

Etchegary, H., Miller, F., Wilson, B., Carroll, J., & Cappelli, M. (2009). Decision-making about inherited cancer risk: Exploring dimensions of genetic responsibility. *Journal of Genetic Counseling, 18*(3), 252–264.

Fernandez, A., Schillinger, D., Warton, E. M., Adler, N., Moffet, H. H., Schenker, Y., et al. (2011). Language barriers, physician-patient language concordance, and glycemic control among insured Latinos with diabetes: The diabetes study of northern California (DISTANCE). *Journal of General Internal Medicine, 26*(2), 170–176.

Flores, G. (2005). The impact of medical interpreter services on the quality of health care: a systematic review. *Medical care research and review, 62*(3), 255–299.

Flores, G., Laws, M. B., Mayo, S. J., Zuckerman, B., Abreu, M., Medina, L., & Hardt, E. J. (2003). Errors in medical interpretation and their potential clinical consequences in pediatric encounters. *Pediatrics, 111*(1), 6–14. doi:10.1542/peds.111.1.6.

Frost, C. J., Venne, V., Cunningham, D., & Gerritsen-McKane, R. (2004). Decision making with uncertain information: Learning from women

in a high risk breast cancer clinic. *Journal of Genetic Counseling, 13*(3), 221–236.

Guss, C. D., & Robinson, B. (2014). *Predicted causality in decision making: The role of culture. Frontiers in Psychology*, 5. doi:10.3389/fpsyg.2014.00479.

Hesse-Biber, S., & An, C. (2016). Genetic testing and post-testing decision making among BRCA-positive mutation women: A psychosocial approach. *Journal of Genetic Counseling*, 1–15.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research, 15*(9), 1277–1288.

Hunt, L. M., Voogd, K. B., & Castañeda, H. (2005). The routine and the traumatic in prenatal genetic diagnosis: Does clinical information inform patient decision-making? *Patient Education and Counseling, 56*(3), 302–312. doi:10.1016/j.pec.2004.03.00.

Jacobs, E. A., Lauderdale, D. S., Meltzer, D., Shorey, J. M., Levinson, W., & Thisted, R. A. (2001). Impact of interpreter services on delivery of health care to limited–English-proficient patients. *Journal of General Internal Medicine, 16*(7), 468–474.

Johnson, A., & Sackett, R. (1998). Direct systematic observation of behavior. *Handbook of methods in cultural anthropology*, 301–332.

Joseph, G., & Guerra, C. (2015). To worry or not to worry: Breast cancer genetic counseling communication with low-income Latina immigrants. *Journal of Community Genetics, 6*(1), 63–76.

Joseph, G., Pasick, R. J., Schillinger, D., Luce, J., Guerra, C., & Cheng, J. K. Y. (2017). Information mismatch: Cancer risk counseling with diverse underserved patients. *Journal of genetic counseling*, 1–15. doi:10.1007/s10897-017-0089-4.

Karliner, L. S., Jacobs, E. A., Chen, A. H., & 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.

Karliner, L. S., Auerbach, A., Nápoles, A., Schillinger, D., Nickleach, D., & Pérez-Stable, E. J. (2012). Language barriers and understanding of hospital discharge instructions. *Medical Care, 50*(4), 283.

Karliner, L. S., Pérez-Stable, E. J., & Gregorich, S. E. (2016). Convenient access to professional interpreters in the hospital decreases readmission rates and estimated hospital expenditures for patients with limited English proficiency. Medical Care.

Kinney, A. Y., Gammon, A., Coxworth, J., Simonsen, S. E., & Arce-Laretta, M. (2010). Exploring attitudes, beliefs, and communication preferences of Latino community members regarding BRCA1/2 mutation testing and preventive strategies. *Genetics in Medicine, 12*(2), 105–115. doi:10.1097/GIM.0b013e3181c9af2d.

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. In *NCES 2006–483*. National: Center for Education Statistics.

Lara-Otero, K., Guerra, C., Cheng, JKY., & Joseph, G. (2017). *Medical Interpretation for Limited English Proficient Patients During Cancer Genetic Counseling: Perspecitves of Genetic Counselors and Interpreters.* Manuscript submitted for publication.

Lewis, L. J. (2002). Models of genetic counseling and their effects on multicultural genetic counseling. *Journal of Genetic Counseling, 11*(3), 193–212.

Lobb, E., Butow, P., Meiser, B., Tucker, K., & Barratt, A. (2001). How do geneticists and genetic counselors counsel women from high-risk breast cancer families? *Journal of Genetic Counseling, 10*(2), 185–199.

Locatis, C., Williamson, D., Gould-Kabler, C., Zone-Smith, L., Detzler, I., Roberson, J., et al. (2010). Comparing in-person, video, and telephonic medical interpretation. *Journal of General Internal Medicine, 25*(4), 345–350.

Lyle, J. (2003). Stimulated recall: A report on its use in naturalistic research. *British Educational Research Journal, 29*(6), 861–878.

Martin, L. T., & Parker, R. M. (2011). Insurance expansion and health literacy. *Jama, 306*(8), 874–875.

Modern Language Association Language Map (2010). Retrieved from http://arcmap.mla.org/mla/default.aspx. Date accessed 6/21/2017.

Nápoles, A. M., Santoyo-Olsson, J., Karliner, L. S., O'Brien, H., Gregorich, S. E., & Pérez-Stable, E. J. (2010). Clinician ratings of interpreter mediated visits in underserved primary care settings with ad hoc, in-person professional, and video conferencing modes. *Journal of Health Care for the Poor and Underserved, 21*(1), 301.

Nápoles, A. M., Santoyo-Olsson, J., Karliner, L. S., Gregorich, S. E., & Pérez-Stable, E. J. (2015). Inaccurate language interpretation and its clinical significance in the medical encounters of Spanish-speaking Latinos. *Medical Care, 53*(11), 940–947.

Nouri, S. S., & Rudd, R. E. (2015). Health literacy in the "oral exchange": An important element of patient–provider communication. *Patient Education and Counseling, 98*(5), 565–571.

Ota Wang, V. (2001). Multicultural genetic counseling: Then, now, and in the 21st century. *American Journal of Medical Genetics, 106*(3), 208–215.

Penchaszadeh, V. B. (2001). Genetic counseling issues in Latinos. *Genetic Testing, 5*(3), 193–200. doi:10.1089/10906570152742236.

Perez, G. K., Mutchler, J., Yang, M. S., Fox Tree-Mcgrath, C., & Park, E. R. (2016). Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters. *Psycho-Oncology, 25*(10), 1241–1245.

Price, E. L., Pérez-Stable, E. J., Nickleach, D., López, M., & Karliner, L. S. (2012). Interpreter perspectives of in-person, telephonic, and videoconferencing medical interpretation in clinical encounters. *Patient Education and Counseling, 87*(2), 226–232. doi:10.1016/j.pec.2011.08.006.

Prucka, S. K., Mcilvried, D. E., & Korf, B. R. (2008). Cancer risk assessment and the genetic counseling process: Using hereditary breast and ovarian cancer as an example. *Medical Principles and Practice, 17*(3), 173–189. doi:10.1159/000117790.

Quan, K., & Lynch, J. (2010). *The high costs of language barriers in medical malpractice*. Berkeley: National Health Law Program, University of California.

Roat, C., Joseph, G., Guerra, C., Cheng, J., Lee, R., & Lara-Otero, K. (2016). *Interpreting for cancer genetics.* Retrieved October 13, 2016, from http://www.chiaonline.org/Interpreting-for-Cancer-Genetics.

Rudd, R. E. (2007). Health literacy skills of US adults. *American Journal of Health Behavior, 31*(supplement 1), S8–S18.

Schensul, S. L., Schensul, J. J., & LeCompte, M. D. (1999). Essential ethnographic methods: Observations, interviews, and questionnaires (Vol. 2). Rowman Altamira.

Seth, S. G., Goka, T., Harbison, A., Hollier, L., Peterson, S., Ramondetta, L., & Noblin, S. J. (2011). Exploring the role of religiosity and spirituality in amniocentesis decision-making among Latinas. *Journal of Genetic Counseling, 20*(6), 660–673. doi:10.1007/s10897-011-9378-5.

Sheets, K. M., Baty, B. J., Vázquez, J. C., Carey, J. C., & Hobson, W. L. (2012). Breaking difficult news in a cross-cultural setting: A qualitative study about Latina mothers of children with down syndrome. *Journal of Genetic Counseling, 21*(4), 582–590.

Silva, M. D., Genoff, M., Zaballa, A., Jewell, S., Stabler, S., Gany, F. M., & Diamond, L. C. (2016). Interpreting at the end of life: a systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited english proficiency. *Journal of pain and symptom management, 51*(3), 569–580.

Stalmeier, P. F., Unic, I. J., Verhoef, L. G., & Van Daal, W. A. (1999). Evaluation of a shared decision making program for women suspected to have a genetic predisposition to breast cancer: Preliminary results. *Medical Decision Making, 19*(3), 230–241. Retrieved January 19, 2015, from mdm.sagepub.com.

Sudore, R. L., Landefeld, C. S., Pérez-Stable, E. J., Bibbins-Domingo, K., Williams, B. A., & Schillinger, D. (2009). Unraveling the relationship between literacy, language proficiency, and patient–physician communication. *Patient Education and Counseling, 75*(3), 398–402.

Underhill, M. L., & Crotser, C. B. (2014). Seeking balance: Decision support needs of women without cancer and a deleterious BRCA1 or BRCA2 mutation. *Journal of Genetic Counseling, 23*(3), 350–362.

U.S. Census Bureau (2015). *Language Spoken at Home, 2015 American Community Survey 1-year Estimates*. Retrieved from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_15_1YR_S1601&prodType=table. Date accessed 6/14/2017.

Van Roosmalen, M. S., Stalmeier, P. F. M., Verhoef, L. C. G., Hoekstra-Weebers, J. E. H. M., Oosterwijk, J. C., Hoogerbrugge, N., et al. (2004). Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. *Journal of Clinical Oncology, 22*(16), 3293–3301.

Veach, P. M., Bartels, D. M., & Leroy, B. S. (2007). Coming full circle: A reciprocal-engagement model of genetic counseling practice. *Journal of Genetic Counseling, 16*(6), 713–728. doi:10.1007/s10897-007-9113-4.

Weil, J., & Mittman, I. (1993). A teaching framework for cross-cultural genetic counseling. *Journal of Genetic Counseling, 2*(3), 159–169.

Xu, K. T., Borders, T. F., & Arif, A. A. (2004). Ethnic differences in parents' perception of participatory decisionmaking style of their children's physicians. *Medical care, 42*(4), 328–335.