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Authors
Cheng, Janice Ka Yan
Guerra, Claudia
Pasick, Rena J
et al.

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ORIGINAL ARTICLE

Cancer genetic counseling communication with low-income Chinese immigrants

Janice Ka Yan Cheng [1,2] · Claudia Guerra [3,4] · Rena J. Pasick [3,4] · Dean Schillinger [5] · Judith Luce [5] · Galen Joseph [1,3]

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Abstract
As genetics and genomics become part of mainstream medicine, these advances have the potential to either reduce or exacerbate health disparities. Relatively, little research has explored the quality of genetic counseling communication experienced by limited English proficiency patients, especially Chinese Americans. We observed and audio recorded genetic counseling appointments (n = 40) of low-income, limited English-proficient Chinese patients (n = 25) and conducted post-visit interviews (n = 17) using stimulated recall to examine patient understanding of the communication. Standard techniques based in grounded theory, including iterative data review and multiple coders, were used to analyze observation fieldnotes and interview transcripts and to identify these themes: (1) strong beliefs in environmental causes of cancer and skepticism about genetic causes, (2) willingness to undergo genetic testing despite skepticism of hereditary cause of cancer, (3) misunderstanding of key information needed to make informed decisions about testing and screening/prevention options, (4) variable quality of medical interpretation, and (5) selective family communication about cancer and genetic counseling and testing. Together, these themes describe substantial gaps in communication and identify the need for genetic counseling techniques and skills that enable counselors to communicate more effectively across language, literacy, and culture. Understanding the mechanisms of inheritance and the implications of genetic test results can be challenging for anyone, and it is exceptionally daunting for those who have limited English proficiency and/or low literacy. For Chinese immigrant patients to reap the full benefits of genetic counseling and testing, effective communication is essential. Research on interventions to improve communication is needed to ensure that disparities do not widen as genomic medicine reaches a more diverse population.

Keywords Genetic counseling · Health literacy · Limited English proficiency · Communication · Hereditary cancer · Health disparities · Precision medicine · Genomic medicine

Introduction

As genetics and genomics increasingly become part of mainstream medicine, these advances have the potential to either reduce or exacerbate health disparities. Studies have shown that women of color and lower income women have less knowledge of and limited access to cancer genetic counseling (GC) and genetic testing (GT) (Walcott et al. 2014; Mai et al. 2014; Cragun et al. 2015). Even where these services are available, uptake may be low compared with white and higher income populations (Sheppard et al. 2013; Butrick et al. 2015; Gaber et al. 2016). While the Affordable Care Act of 2010 and lower costs of testing have made hereditary cancer services more accessible for low-income individuals in recent years (FORCE 2015), access alone may not be sufficient to ensure high quality GC and appropriate testing.

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 (Schillinger 2007; Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association 1999; US DHHS, Office of Disease

✉ Galen Joseph
galen.joseph@ucsf.edu

[1] Department of Anthropology, History & Social Medicine, University of California, San Francisco, CA, USA

[2] Department of Psychiatry, University of California, San Francisco, CA, USA

[3] Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco, CA, USA

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

[5] Department of Medicine, University of California, San Francisco, CA, USA

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Prevention and Health Promotion 2000; Andrus and Roth 2002). Language and cultural differences between patients and providers generate significant barriers to effective communication (Lurie and Dubowitz 2007; Fernandez et al. 2011). Similarly, patients' low health literacy produces significant communication challenges and has been associated with poorer outcomes on a wide range of health conditions (Berkman et al. 2011). The combination of limited English proficiency (LEP) and limited health literacy appears to have synergistic effects (Sudore et al. 2009).

Asian-Americans are the second fastest-growing group in the USA (Colby and Ortman 2015). Nearly three quarters are foreign-born and almost half have LEP (Pew Research 2012). In 2011, California had the second highest percentage (10%) of foreign-born Asian-Americans after Hawaii (14%) (Gryn and Gambino 2012). Chinese Americans are the largest sub-group in the USA and make up about 24% of the adult Asian-American population (Pew Research 2012). While data are limited, the prevalence of BRCA1 and BRCA2 mutations among Chinese familial breast and ovarian cancer patients appears to be similar to those of European and American populations (Kim et al. 2016), as does the prevalence of Lynch syndrome among Chinese colorectal cancer patients and kindred (Zhang et al. 2005). Given these population trends and the mutation prevalence in the most common hereditary cancer syndromes, genetic counselors (GCs) are increasingly likely to provide services to Asian-Americans, especially LEP Chinese Americans.

Barriers to effective use of GC/GT have been identified among underserved Asian-American patients, including low levels of awareness of GC/GT at the time of referral, difficulty understanding the cancer risk indicated by the test results, incompatible beliefs about the causes of cancer, concerns about misuse of genetic information, and unfamiliarity or discomfort with Western preventive medicine (Glenn et al. 2012; Mai et al. 2014). A 2009 study found that 48% of whites had heard of GT, compared with only 28% of Asian-Americans, a gap partially explained by nativity/length of residence in the USA (Pagán et al. 2009). In a study of highly educated Chinese-Australians, incompatible beliefs about inheritance and kinship between "Western" and Chinese cultures limited the benefits of cancer GC (e.g., prevention and cascade testing) (Eisenbruch, et al. 2004). Fehniger et al. (2013) identified significantly lower rates of family communication about BRCA test results among Asian/Pacific Islander and African-American patients compared with other groups. Because GT relies heavily on patient reports of family history, such findings may partially explain why the BRCA mutation prediction models based on personal and family cancer history are less accurate in Asian-Americans (Kurian et al. 2008) and Hong Kong Chinese (Kwong et al. 2012).

If patients of varied cultural backgrounds, LEP, limited literacy, and/or low-income are unable to benefit from genetic risk services in the same ways as those who are white, affluent, English proficient, and highly literate, advances in genomics may exacerbate current disparities in genetic testing for hereditary cancer and thus in cancer outcomes overall. To our knowledge, ours is the first study to examine the communication between GCs and low-income Chinese immigrants as they undergo cancer risk counseling (Meiser et al. 2008; Paul et al. 2015). The purpose of our study was to examine the dynamics of GC patient communication in real time and explain how and why it was or was not effective.

Methods

Setting and population

The data were collected as part of a larger study of communication in cancer genetic counseling in public "safety net" hospitals that employed ethnographic observations of clinical appointments and in-person qualitative interviews with patients and counselors (Joseph et al. 2017). All English-Spanish and Chinese-speaking patients who had appointments when a language concordant researcher was available were eligible for the larger study. This article analyzes data collected with the Chinese speakers who were recruited at one of the participating hospitals where GC and GT are available to patients free of charge through a variety of means, including MediCal (California's Medicaid program), Medicare, county health programs, laboratory hardship programs, and foundation support. The GCs are employed by an affiliated academic medical center and specialize in hereditary cancer. Patients are referred to counseling from mammography, primary care, oncology, and community clinics and may be unaffected or affected with a cancer diagnosis. GCs typically see a patient for two or three appointments, including (1) an information and education (pre-test) appointment to discuss family history, risk assessment, hereditary cancer, and GT; (2) a second pre-test appointment to update family or medical history and review/revise risk assessment and GT if not previously done; (3) a results appointment (results) to discuss implications of test result for the patient and family, as well as screening and prevention options. For LEP patients, remote professional medical interpreters are available by telephone or video.

All research procedures for this study were approved by appropriate Institutional Review Boards. We obtained verbal informed consent for observations and written consent for interviews. In accordance with our IRB approved protocol, all proper names are pseudonyms, and we have changed potentially identifying characteristics to protect individuals' identities.

Data collection

From November 2012 to April 2015, we directly observed and audio recorded GC appointments and conducted post-visit qualitative interviews with patients offered testing. We aimed to follow participants through the counseling

process, observing as many of their appointments as possible and interviewing them after each observed pre-test or results appointment. As a result, several participants were observed and interviewed more than once. We used standard ethnographic observation techniques designed to minimize the impact of the research on the care received by participants and to ensure that the data reflected usual care routines (Atkinson and Hammersley 1994; Denzin and Lincoln 1998; Johnson and Sackett 1998). Twelve out of 40 observed sessions were not audio recorded in accord with patient preference. In these cases, the researcher took detailed fieldnotes to record the dynamics of the session, communication challenges, emotional tenor, body language, etc. (Emerson et al. 1995). During the period of study, four GCs conducted the sessions we observed.

Observed patients who were offered and accepted GT were invited to participate in a post-visit qualitative interview. When audio recording was available (11 out of 17 interviews), we employed the stimulated recall method in which the patient listens to key segments of the audio recording of the GC session, and the interviewer elicits reactions and thoughts about them (Lyle 2003; Saba et al., 2006). Interviews were conducted in Cantonese and took place as soon as possible after the appointment (median = 9 days, range 0–76 days). Topics included: (1) experience with GC and GT; (2) understanding of cancer inheritance and beliefs about the causes of cancer; (3) risk perceptions; (4) understanding of test results and screening recommendations; and (5) personal history and sociocultural and socioeconomic context of daily life. Interview questions were tailored based on fieldnotes and key segments of the audio recording, which were selected for stimulated recall (e.g., GC explanations of cancer heredity, risk, genetics, test results, and screening/prevention recommendations). Participants were compensated for their time with a $25 grocery store gift card for each interview.

At the end of the first interview with each patient, we administered a demographic survey and the Subjective Numeracy Scale (SNS) (Fagerlin et al. 2007). The SNS measures self-perceived ability to perform mathematical tasks and preference for numerical rather than prose information. It consists of eight items (four require participants to evaluate their numerical ability in various settings, and four require participants to indicate their preferences for the presentation of numerical information as numbers or prose). Each question is scored on a 6-point Likert-like scale, and the overall score is computed as the average rating across all eight questions (with one question reversed scored). SNS has been shown to correlate with objective numeracy (Fagerlin et al. 2007) and has been validated in English only (Zikmund-Fisher et al. 2007). We used a professional translation of the SNS to Chinese.

Data analysis

Demographic characteristics and SNS scores were calculated for interview participants. Digitally recorded interviews were translated/transcribed verbatim for analysis by professional bilingual transcribers. Transcripts and notes from the unrecorded interview were coded and analyzed using Atlas-ti v.6.2, a qualitative data analysis software program. We followed standard techniques based in grounded theory, including iterative data review, and use of multiple coders to identify the themes described and illustrative quotes included below (Bernard 2006; Glaser and Strauss 1967; Strauss and Corbin 1990). Each transcript was read by three members of the research team and coded by at least two, who also wrote interim analytic memos. Coders included the first author, a bilingual bicultural (Cantonese/Chinese) social psychologist, and bilingual/bicultural (Spanish/Latina) research associate and the PI, a medical anthropologist. Coders independently reviewed the initial transcripts using a combination of open coding and a priori codes based on the interview guide, the literature, and preliminary research (Joseph and Guerra 2015). Coders then met to reconcile discrepancies and establish a codebook. Examples of commonly used codes include the following: GC explanation of possible test results, GC explanation of screening/prevention options, patient information needs, patient understanding of genetic test, and patient understanding of screening/prevention options. Subsequently, coders independently coded using the codebook and then met to reconcile discrepancies, to discuss adding new codes as needed, and to discuss coding memos which described emerging themes.

Results

Participant characteristics

We observed 40 GC sessions with 25 Chinese patients (14 patients were observed in one session, 7 in two sessions, and 4 in three sessions) (see Fig. 1). Nine family members were present in at least one GC session (six husbands, one daughter, one sister, and one mother). All sessions were conducted in a Chinese dialect (37 in Cantonese, 2 in Toisanese, and 1 in Mandarin) via a professional medical interpreter by phone (32 sessions) or video (6 sessions). A patient navigator and a bilingual family member who was also a nurse served as interpreter for one session each. Nine participants were interviewed once (five after pre-test, four after results), four were interviewed twice (after both pre-test and results) for a total of 17 interviews.

Demographics of interview participants ($n = 13$) are detailed in Table 1. All participants were women. Twelve patients had been diagnosed with cancer, and one unaffected

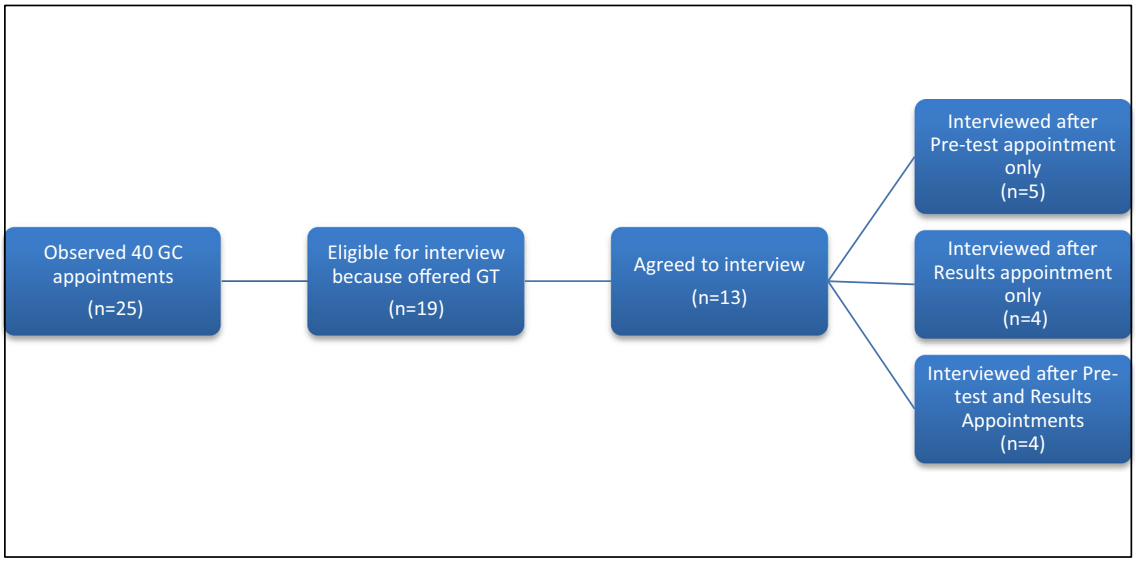

Fig. 1 Observations and interviews

patient was referred due to family history. Ages ranged from 36 to 72 years. Only two had a college education. The participants' scores on the overall SNS ranged from 1.63 to 5.13, with an average of 3.66 (*SD* = 1.06) (the SNS score from one participant was missing). For comparison, in the original scale development article, Fagerlin et al. (2007) reported an average score of 4.03 (*SD* = 1.04; range = 1.00 to 6.00) in a sample with higher levels of education (72% self-identified as white, 52% had some college, 10% had at least a bachelor's degree). The four participating GCs were all white women, in practice for 4–25 years.

During our data collection period, the hospital (like the larger field of hereditary cancer risk assessment) shifted from "single gene testing" (i.e., testing the BRCA genes or Lynch syndrome genes) to multiplex "panel testing" (i.e., testing multiple genes at once) as the standard care for patients. Thus, the first four interview participants received BRCA1/2 testing, and the subsequent nine interview patients received a panel test. Of the 13 interviewed patients, five were negative, one was positive for BRCA2, two were positive for Lynch syndrome, and five received a variant of uncertain significance (VUS) in other genes (APC, CHEK2, NBN, BRIP1, MUTYH).

Key qualitative themes

Analyses of the observation fieldnotes and interview transcripts, which included segments of the audio recorded counseling sessions, resulted in five key themes: (1) strong beliefs in environmental causes of cancer and skepticism about genetic causes, (2) willingness to undergo genetic testing despite skepticism of hereditary cause of cancer, (3) patients misunderstood key information provided in GC needed to make informed decisions about testing and screening/prevention options, (4) variable interpreter quality limits understanding and reinforces misconceptions, and (5) selective family communication about cancer and GC/GT. Unless otherwise noted as an audio recording of the GC session, the quotations are derived from patient interviews.

Strong beliefs in environmental causes of cancer and skepticism about genetic causes

Despite having a basic conceptual understanding of heredity (i.e., that diseases can run in families), most study participants attributed their own cancer to environmental factors, such as diet, stress, and a weak immune system, and expressed skepticism about genetic causes even after positive genetic test results. Several participants were referred to counseling due to their young age at diagnosis, but did not have a known or strong family history, and thus had no reason to think that they inherited a disposition for cancer. Despite the GCs attempts to explain that an early-onset diagnosis can indicate a hereditary mutation even without a known family history, these patients persisted in their beliefs about environmental causes. For example, one 41-year-old patient who had no known family history of cancer believed her cancer developed due to the stress of living with her mother-in-law who had dementia.

> The reason that I might have developed this illness over the past ten years was stress…I have been here for eleven years, and [my parents-in-law] have lived with us for three years…These past three years, I have been feeling worn out, because my mother-in-law lost her memory. From midnight to four in the morning, she would talk non-stop. Even though she is downstairs and my husband also installed panels to absorb the noise, I could

Table 1 Interview participant demographics (n = 13)

	Mean (range) or n (%)
Age	55.5 (36–72)
Marital status	
Married/with a long-term partner	10 (90.9)
Never married	0 (0)
Legally separated or divorced	0 (0)
Widowed	1 (9.1)
Unreported/missing	2 (0)
Education	
Less than high school	5 (41.7)
High school or equivalent	4 (33.3)
Some college or higher	2 (16.7)
Other (vocational school)	1 (8.3)
Unreported/missing	1 (0)
Foreign born	
Yes	13 (100)
No	0
Years in the USA	14.8 (1–37)
Language(s) spoken at home	
Only non-English/more non-English language than English	13 (100.0)
Both equally	0 (0)
Only English/more English than non-English language	0 (0)
Preferred language with your doctor and nurses	
Cantonese/Mandarin	13 (100.0)
Subjective numeracy	
Range	1.63–5.13
Mean	3.66 (1.06)
Cancer status	9 breast 1 ovarian/uterine 1 colon 1 rectal 1 unaffected
Test results	
Positive	3 (1 HBOC; 2 Lynch)
Negative	5
VUS	5

> still hear it. I wake up every hour from the noise…And maybe because I didn't sleep well, those kinds of things come. [19-CHI, pre-test].

Even some older patients with a family history of cancer ascribed the cancer to environmental causes. A 65-year-old patient with breast cancer whose father and brother both died of cancer believed that she and her brother had developed cancer due to a combination of stress and dietary factors, and she blamed her father's cancer on the suffering he had endured during China's Cultural Revolution.

> I think the reason I had breast cancer was not because of my genes. I have been working hard for many years, and the fatigue is catching up to me. Also, air pollution and genetically modified foods may be attributed to breast cancer. I think that a lot of people are diagnosed with breast cancer in America. The food here should be safer than other countries but I don't understand why there are still so many people with breast cancer…I think if my father wasn't forced to do farm work during the Great Cultural Revolution and he stayed in Guangzhou working a stable job and had the family as a whole together, he might not have gotten cancer. The main reason he had cancer was because he wasn't happy and was treated unfairly… If a person continues to be wrongfully accused of doing something and remains depressed all the time, even a healthy person can develop an illness. I think that my father had cancer because he was under constant accusations. My brother, however, it was because he was a businessman so he had to eat out and drink a lot. He also didn't get much rest, and the stress from work caused his cancer. He wouldn't have gotten cancer if he could have retired earlier. I don't think my family carries the cancer gene. [15-CHI, pre-test].

A 63-year-old patient with ovarian and uterine cancer implied that cancer was caused by a weak immune system vulnerable to a virus, as well as bad luck.

> Interviewer: At first you brought up the idea that you get cancer because you're unlucky. Can you tell us why you think so?
> Patient: (Chuckles) I guess this is just a superstition that someone is unlucky.
> Interviewer: (Chuckles) Can you share with us what you mean by that? […].
> Patient: I guess it's just because our immune systems are weak.
> Interviewer: But having a weak immune system and having bad luck are two different things. Can you share with us more about what you meant?
> Patient: Well it's unlucky that your immune system is weak. When your immune system is weak, then the virus and things go into your body. [7-CHI, pre-test].

When the interviewer asked a 68-year-old who had received a VUS in a Lynch syndrome gene if she recalled the three possible test results the counselor had explained, her response made it clear that she had not understood her

VUS result and that she believed a poor diet could cause cancer.

> I think the first one is negative and the second is something and the third is something. *(Laughs)* The second one is maybe due to unhealthy diets. [9-CHI, results].

After further investigation by her GC, her VUS result was determined to be deleterious, and she received a Lynch syndrome diagnosis a week after having received the VUS result. Nevertheless, she continued to blame her cancer on eating oily food in the cafeteria of the factory where she had worked for 26 years.

Many patients continued to view lifestyle and dietary changes as the primary mode available for cancer prevention, rather than prophylactic surgery or intensive screening regimes described by the GCs. As one patient with breast cancer said after her pre-test appointment, "If cancer is hereditary in my family, then I would have to watch out for my diet and my lifestyle habits." [8-CHI, pre-test]. Importantly, the patients' beliefs about the causes of cancer rarely emerged in the counseling discussions; counselors' rarely elicited patients' beliefs, and patients did not offer their perspective.

Willingness to undergo genetic testing despite skepticism of hereditary cause of cancer

In spite of their skepticism about hereditary roots of their cancer or a hereditary risk of cancer in the future, all participants who were offered testing agreed to it. With no financial barrier (due to Medicaid or Medicare coverage or foundation or laboratory support), patients saw little reason to decline testing, even when they perceived little benefit. For example, one 68-year-old breast cancer patient with a strong family history appeared quite interested in genetic testing during her GC appointment told the interviewer that she only agreed to be tested because it was covered by her insurance. Several others agreed to test with the expectation that the result would be negative, as in the case of this 41-year-old patient with breast cancer.

> Well to see if I had that thing, you know, to confirm that I didn't have the genes and if I didn't then I would be very relieved. [4-CHI, pre-test].

While such patients understood that hereditary cancer could affect their children, they typically used vague language when explaining how they might talk to their children or grandchildren about the cancer in the family. In most cases, patients indicated that they would only talk about health or cancer in general, rather than about a specific hereditary cancer risk with children and other family members, as in the case of this 68-year-old with breast cancer.

> Well in my generation alone, three family members have cancer. And so far in my nephews' generation, one has cancer. Therefore, I would like to understand if these cancers are hereditary or if they arose from lifestyle habits. If I knew the cause, I would be able to remind them. [8-CHI, pre-test].

This vague language about "reminding" family members so they could be "more aware" may have been due to the limited understanding of screening and prevention recommendations described by the counselors, as we discuss in theme 3 and due to the stigma of (hereditary) cancer, as discussed in theme 5.

Misunderstanding of key information needed to make informed decisions about testing and screening/prevention options

Patients in our study frequently misunderstood a range of key information provided in GC. Some of the information was needed to make an informed decision about GT, including the purpose of GC and GT, the basics of cancer heredity, and the implications of test results for self and family members. For example, one 52-year-old patient with ductal carcinoma in-situ (DCIS), still believed BRCA1 and 2 were like type 1 and type 2 diabetes after two pre-test appointments.

> Because she didn't say what one is and what two is [in BRCA1/2]. She didn't say anything about that. …I've heard about diabetes. Diabetes has a Type 1 and a Type 2. Type 1 is from the genes, for example, if your mother or father has it, then it can be passed on. Type 2 is a result of what you eat, like if you don't watch what you eat. Could it be like that? That's what I think. Even though she didn't say what one is and what two is, it reminds me of that. [22-CHI, pre-test].

This patient, who had less than a high school education, also thought the GT looked for cancer in the genes. When asked to explain her understanding of the purpose of GT, she told the interviewer:

> I mean whether the gene has cancer or not. They are checking the genes for cancer, whether there is or there is not. That's my understanding. [22-CHI, pre-test].

Some but not all of our participants shared her fundamental misunderstanding of the genetic test as checking for cancer rather than the risk of cancer. A 41-year-old, college-educated woman, who was recently diagnosed with DCIS, understood

that "Not everyone who carries the cancer genes will get cancer but chances of getting it are higher." [19-CHI, pre-test]. However, she remained under the impression that the GT result would explain the probability of her cancer recurring. Although she asked the GC about it, she did not feel that she received a clear answer. (Note that in the following and subsequent quotes, we include "interpreter" in parentheses to indicated when the GC or patient paused to let the interpreter translate.)

Audio playback of counseling session during the interview:

> GC: This testing that I'm going to talk about doesn't really answer the question about recurrence of your cancer. (*Interpreter)* Whether your cancer comes back or not is really more related to the type of cancer and what stage it was when it was diagnosed. *(Interpreter).*

Stimulated recall interview:

> Interviewer: This segment [of the GC session] goes back to when you were expressing your worries about the recurrence of your cancer. What do you think [the genetic counselor] was trying to explain to you?
> Patient: From this segment, I found out that [the genetic counselor] would not give me a sure answer. She would not tell me specifically the percentage chance that my cancer would come back. She had to look at the report. It also depended on what type of cancer I had, what stage it was, and whether or not it was discovered early enough. She would have to look at all of that before telling me an answer. That was what she said. [19-CHI, pre-test].

Here, the GC offered additional information about the factors that may influence risk of recurrence but did not effectively clarify the patient's misconception. Like many patients, she mistook the risk of a new cancer in a different organ (a "second primary" that could be part of a cancer syndrome like HBOC or Lynch) for the risk of recurrence. For a 68-year-old colon cancer patient diagnosed with Lynch syndrome, this misunderstanding made it difficult to see how she could benefit from a hysterectomy.

> Patient: Right. She recommended that I remove my uterus, but I didn't want to.
> Interviewer: Why do you think she recommended you to remove it?
> Patient: Well if I remove it, then [the cancer] wouldn't go there. I didn't think it was necessary, since it can go anywhere. If it doesn't go to the uterus, it will go to the ovaries and my ovaries are in the same area. I don't think it's necessary. [9-CHI, results]

Her statement reveals that she did not understand concept of a hereditary cancer *syndrome,* like HBOC or Lynch. She remained concerned that her cancer would spread but did not understand that she was at risk for new primary cancers.

In several cases, we saw patients ask appropriate questions, only to receive vague or indirect responses from the GC. In one such case, after the GC recommended that a patient's sisters start having mammograms at age 35 years, the patient asked whether her 21-year-old daughter also should begin mammography when she reached 35 years old.

Audio playback of counseling session during the interview:

> Patient: So that means my daughter would also have to get her mammogram exam when she turns 35? (*Interpreter).*
> GC: How old is your daughter now? (*Interpreter).*
> Patient: She's 21 years old. *(Interpreter).*
> GC: Okay, so hopefully in the next 14 years, we will have gotten much better at detecting breast cancer and DCIS, so I think the best thing for her is to make sure her doctor knows about her family history of DCIS. And then when she gets closer to age 35, she can get the best recommendations for whatever we have available at that time. *(Interpreter)* [22-CHI, results].

In our interview with the patient, she said that she felt the GC did not directly answer her question.

> She didn't really answer my question. She only told me that medical technology may improve in the future, so it would be better. She also said she needed to speak to my primary care physician about my family healthy history. [22-CHI, results].

The patient seemed to want the GC to provide a more concrete and clear response to address her immediate concern about her daughter. The GCs' efforts to convey the nuances, uncertainty, and evolving science of genetics often left patients confused.

Variable quality of medical interpretation

The misunderstandings described in the previous theme were exacerbated by the variable quality of medical interpretation we observed. Poor interpretation negatively impacted the patients' understanding and the ability of the counselor and patient to develop rapport and sustain a dialog. Interpreters participated in counseling remotely by phone or video. Technological and audio problems at times made it difficult to hear and increased the likelihood of mishearing or misunderstanding what was said. For example, the pronunciations of positive (*yeung sing*) and benign (*leung sing*) sound similar in

Cantonese and patients sometimes misheard the interpreter over the phone. On one occasion, we observed a dialect difference between the interpreter (Cantonese) and patient (Toishanese). One participant indicated that she was reluctant to ask questions because the interpreter was not in the room with her.

> It would be best if the interpreter could be present in the room instead of over the phone so that I could understand more clearly and ask more questions. I don't feel as comfortable asking questions over the phone. If the interpreter was actually in the room, it would be a lot better. […] I'm afraid to ask questions over the phone. [10-CHI].

Interpreters' limited understanding of genetics created additional communication barriers. Interpreters, like some patients, sometimes mistook the risk for carrying the gene mutation with the risk for getting cancer. Jargon and technical language could lead to confusion, with critical terms like "genes" incorrectly interpreted as "cells," and positive and negative reversed. The term "variant of uncertain significance," which is conceptually challenging, also has no direct translation in Cantonese. In the following example, the interpreter seems to completely misunderstand the counselor.

Audio playback of counseling session during the interview:

> GC: The third type of results is maybe the most frustrating result is called a variant of uncertain significance.
> Interpreter: But the third choice sometimes is that breast cancer cannot be prevented.
> GC: So, this doesn't happen very often but sometimes we send someone's blood to the laboratory and they find the genetic change but they don't know if it increases the chances of cancer or not.
> Interpreter: But sometimes, separating one pair from another, if the reason…know that there is a big risk of maybe getting this illness but sometimes can't prevent it. [CHI-10].

In the next example, the medical interpreter inserted the idea that mutations may be due to an old immune system. As discussed above (theme 1), the notion of immune system involvement in cancer was not unique to this interpreter.

Audio playback of counseling session during the interview:

> GC: But sometimes there can be what's called a mutation or a change in the gene so it doesn't work properly.
> Interpreter: Usually regarding our immune system, after a long time and we get old and things change then these genes…cannot protect. [4-CHI, pre-test].

In the following case, we saw an interpreter apply his own misunderstanding of genetics rather than directly interpret the GC's statement.

Audio playback of counseling session during the interview:

> GC: So we have a very new test that is available here for our patients at [our hospital] looking at twenty-six genes that have been connected to cancer.
> Interpreter: Now we have a new medical exam that has to see your…those genes, those chromosomes. Twenty-six pairs. [10-CHI].

While misinterpretations that inserted new ideas were relatively rare, they suggest misunderstandings of cancer and genetics on the part of the interpreters, like the patients, that the counselors' educational efforts were unable to engage or overcome.

A further challenge for the medical interpreters was the GCs' efforts to convey nuances and uncertainty. We observed that interpreters often attempted to make uncertainty more concrete, e.g., translating estimates such as "5–10%" more simply as "10%." We also saw interpreters sometime skip analogies, which were not always culturally relevant, and hypotheticals, which often involved complex grammatical constructions and multiple if/then statements, rendering them difficult to translate. The counselors' reliance on analogies and hypothetical scenarios, as well as efforts to convey the many nuances and significant uncertainty of genetic information, challenged both patients' and interpreters' ability to understand and patient engagement with the counselors.

Selective family communication about cancer and GC/GT

Many patients selectively disclosed their cancer diagnosis and genetic test results to family and friends. The key reasons for selective disclosure included concerns that (a) sharing their cancer status with any relatives would lead to disclosure to their elderly parents, (b) elderly parents' knowledge of the cancer diagnosis or genetic test results would cause them to worry without any benefit, especially if their parents were overseas, and (c) relatives' belief that cancer is contagious and thus would stigmatize the patient or otherwise negatively impact the relationship. As a result, patients tended to share their cancer diagnosis and/or genetic test results with only a small group of people whom they trusted and whom they believed would not spread the news in their social networks. For example, in the following excerpt, the counselor tried to ascertain the accuracy of the family's cancer history in order to assess risk for a BRCA mutation and determine whether to offer the genetic test.

Audio playback of counseling session during the interview:

> GC: So if there were cancer in any of your aunts or uncles in China or any of their children, your cousins, do you think you will know that for sure? *(Interpreter).*

Patient: Yes, I will know, because we often chat on WeChat [a popular instant messaging app in China] or talk on the phone. (*Interpreter).*
GC: So they know you're going through this diagnosis. *(Interpreter).*
Patient: They only have cardiovascular problems like high cholesterol and high blood pressure. (*Interpreter).*
GC: But they know about your diagnosis with breast cancer? (*Interpreter).*
Patient: No, I didn't tell them (*Interpreter)*. It's not because I want to hide anything from them, but the culture that they grew up in is not as open-minded, and I am afraid that they would say something to my mother that would affect her emotions. (*Interpreter).*
GC: The reason I bring that up is, as you point out, sometimes we're very private and we don't share that information. So, is it possible that maybe someone in China had that happen and didn't share it with you for the same reason? (*Interpreter).*
Patient: No, because my mother is the big sister, so she is the oldest child. Her younger brothers and sisters would tell her whenever anything happens. (*Interpreter)* [19-CHI, pre-test].

The patient feared that if she shared the information with anyone in China, her relatives would tell her elderly mother, whom she wanted to protect from the worry this news would cause. In her interview, she also disclosed that overreaction and concern from friends and relatives could generate pressure and discomfort.

My uncle and aunt only have high blood pressure and high blood lipids level and that has become a pretty big deal already. They talked to my mother on the phone for over an hour about it, so I don't want them to talk to my mother for so long again and tell her to tell me to be careful of my diet and things like that. If I'm being monitored what I do, I would feel pressured. My mother is healthy now, so I just want her to stay like that, because that actually helps me. [19-CHI, pre-test].

After another participant tested positive for BRCA2, the GC suggested that she tell her cousin who had been treated for breast cancer before emigrating to New York. However, the patient did not want to share her test results until after completing her own treatment. She worried that if her cousin learned about her cancer, her elderly parents would find out too.

Audio playback of counseling session during the interview:

GC: And does she know about [your] test results? (*Interpreter).*
Patient: No, I didn't tell her. (*Interpreter).*
GC: So she is a really important person to inform about this. *(Interpreter).*
Patient: Right, I was going to inform her after I had my surgery. *(Interpreter)* I will tell her, but I want to take care of my own business before telling them anything. I don't want to tell them when I'm still sick now. I don't want them to start talking and things like that. *(Interpreter)* Because if they know, they would tell my parents. (*Interpreter*) [My] parents are 80 years old. My older brother and I are both here, and they are in China by themselves, so I don't want them to [know]…because they are old. (*Interpreter)* Right, they are 80 years old. That's why I have to take care of my own business first, and when I'm all better, I can tell them. (*Interpreter).*
GC: Okay, I understand why you want to wait then. (*Interpreter)* But after your surgery, the cousin with breast cancer is probably the most important person to tell right away. (*Interpreter)* [16-CHI, results].

Here, the counselor tried to impress upon the patient the need to inform her cousin, whose diagnosis of breast cancer suggested that she might also be a BRCA carrier who could directly benefit from the knowledge. However, the counselor did so with an understanding of the cultural context, and the patient's need to protect her parents from the news about her cancer. The patient indicated that she would share her test results with her cousin after she completed her cancer treatment, when she could tell them "everything is okay with me for now" and if news of her illness reached her parents, they would not have reason to worry.

Two participants in our study were reluctant to share information about their cancer diagnosis because their relatives believed cancer was contagious. One participant, who was diagnosed with colon cancer in China before emigrating to the USA, was concerned (along with her husband) that revealing her cancer diagnosis would damage their relationships with certain relatives. Thus, she and her husband only shared her cancer diagnosis with one brother-in-law whom they really trusted.

Interviewer: I understand that last week [during the GC session], you had concerns about confidentiality and you worried that your information would be disclosed to other people. Can you tell me why you had these worries?
Patient's husband: Well, the people who know [about her cancer] are not very knowledgeable and they may misunderstand us, so we try not to let that many people know. People may think that [cancer] is contagious so that may cause some misunderstanding toward us. [9-CHI, pre-test].

When asked to explain further, the patient expressed concern about her in-laws' lack of knowledge about cancer.

> You have to know, they're not like me and my husband. For example, his brother and his wife. If they're like me, I can definitely tell them. They don't know the facts and if I tell them, they might think "oh, you have cancer, I'm not going to go near you, and I'm not going to touch the food that you ate." They don't know the information. That's why it's better not to tell them. If they know the information then I don't mind telling them. [9-CHI, pre-test].

Her husband later elaborated that they did not tell certain family members in order to preserve their relationships, which would likely be damaged if they learned of the diagnosis.

> Patient's husband: …They would look at us differently if we tell them, since their education level is limited and they don't understand these things. As a result [of not telling them], there wouldn't be as much stress on us. If they don't know, we would get along fine, and it would be better. [9-CHI, results].

Such examples reveal a considered process of selective disclosure to family members near and far, taking into account relatives' cancer knowledge, age, and ability to act upon the information.

Discussion

Genetic counseling, testing, and associated screening, as well as treatment and preventive measures have been shown to reduce morbidity and mortality and to improve quality of life for those with hereditary cancer syndromes. As a result, they have become standard of care. To realize the full benefits of genetic and genomic medicine, the increasingly diverse patients who are gaining access to these services must be able to benefit fully from them. Our findings reveal substantial gaps in communication, and the need for genetic counseling techniques and skills that enable counselors to communicate more effectively across language, literacy, and culture.

Although many study participants left counseling with a basic understanding of hereditary cancer (e.g., cancer can run in a family and carrying the "cancer gene" can impact children and grandchildren), they also retained some important misconceptions, including misunderstandings about the purpose of genetic testing and the implications of test results for cancer risk, screening, and prevention. The counselors in our study, while at times showing great cultural sensitivity (e.g., regarding the difficulty of family communication), often did not recognize the variety of misconceptions and beliefs we identified. Patients' beliefs about cancer and their skepticism about genetics rarely emerged in the counseling sessions we observed, making it difficult to bridge the distinct worldviews of the GCs and the patients. For example, patients' strong belief that their cancer was due to environmental and/or behavioral factors did not change after counseling, even among some who tested positive. Interpreters' misconceptions and misinterpretations could exacerbate patient confusion and were difficult for the GC and patient to recognize given the language gap. The new information provided by the counselor was not integrated into their existing belief system. In the current GC practice model, a significant portion of the session focuses on providing education about genetics, rather than on understanding patients' expectations and assumptions (Riley et al. 2012).

Despite their lack of understanding and interest in the educational portions of the GC (Joseph et al. 2017; Karmara et al. 2017), most patients were receptive to the GT offer. They anticipated feeling relieved if the test results were negative. Facing no financial barrier, they saw little reason to decline the test. If they carried the mutation, patients indicated that they would use the information to "remind" future generations to be more "careful" or "cautious." These vague terms reflected the patients' belief that there was not much they or their relatives could do if they did carry a deleterious mutation. Our participants generally assumed that the purpose of the GC appointment was to undergo testing rather than to make a decision about testing. This expectation may partially explain why many were not motivated to ask for clarification when they did not understand the counselor's educational efforts. Even when patients did ask questions, the GCs' explanations did not always clarify patients' confusion.

The seemingly contradictory desire to find out if they carry the mutation, and the belief that there is not much they can do if they have it, is consistent with the Chinese philosophical concept of *Ming* or "fatalistic voluntarism" which combines acceptance of life circumstances and exertion of personal efforts to change the circumstances. Cheng et al. (2013) found that Chinese women with breast cancer perceived an inability to change the outcome of their cancer and, yet, also actively engaged in emotion-focused (e.g., having a positive attitude) and problem-focused coping strategies (e.g., engaging in self-care activities such as dietary changes and physical activities in addition to standard treatments). This apparent contradiction between a fatalistic acceptance of what is and an active engagement in coping strategies is similar to findings for women in Europe and the USA (Deimling et al. 2006; Manuel et al. 2007; Zucca et al. 2010). A worldview that reflects the concept of *Ming* is not equivalent to passively accepting whatever happens in life, as suggested by the Western concept of fatalism (Powe and Finnie 2003). Among our participants, *Ming* seemed to be supported by a limited understanding of preventive measures for hereditary

cancer, as well as the socioeconomic reality of their adult children and other relatives who either did not have access to cancer risk services in China or no time to seek them due to the demands of work in the USA.

Consistent with previous findings that Asian-Americans were less likely to disclose their test results with family members than other race/ethnic groups (Cheung et al. 2010; Fehniger et al. 2013), many patients in the current study expressed concerns about sharing their cancer diagnosis and genetic test results with family members. According to one study conducted with cancer patients in China, the patients expressed concerns that their family members experienced "equal suffering" in their cancer journey, and they did not want to be a burden to their family members (Lee and Bell 2011). Conditions of immigration or diaspora create an additional barrier to sharing information about cancer or GC/GT among family members. The patients in the current study intended to protect their elderly parents (especially if they lived overseas) by withholding their cancer diagnosis. The patients also wanted to protect themselves from the social stigma associated with cancer. The lack of family history of cancer which we observed in some patients may be a lack of *known* family history due to customs of not talking about cancer, lack of access to medical care and concrete diagnoses, and/or small families. Selective family communication about hereditary cancer counseling and testing can limit the possibility of cascade testing and the potential for prevention among family members. The GCs in our study were particularly skilled in assessing the accuracy of family medical history in a culturally appropriate and sensitive manner. They expressed empathy when patients indicated difficulty communicating about cancer within the family, probed whether cancer was a topic that the patients and patients' family members would openly discuss, and encouraged patients to obtain additional medical information or share their test results with family members when possible.

Limitations

The current study has some limitations. It was conducted at one public hospital with a small sample of counselors and patients. As a result, the communication barriers we documented may be influenced by the practices of the participating counselors and interpreters, and the culture of the institution where they worked. Most patients were originally from the Guangdong Province, China. Thus, the findings may not reflect the experiences of Chinese immigrants from other geographical origins or destinations within the USA. Nevertheless, the consistency in the content of the counseling sessions and in the responses of the patient participants led us to identify strong patterns presented in the themes described here. Six out of 17 interviews were conducted without stimulated recall because the patients declined to be audio recorded during the GC session. This rate was higher than those for English- and Spanish-speaking patients in our larger study (Joseph et al. 2017). The presence of researchers during the counseling sessions may have influenced counseling dynamics in ways for that we cannot know. Despite these limitations, the current study documented communication dynamics between GCs and Chinese immigrant patients in real time, which represents a significant advantage over prior studies that focused on English-speaking patients and were conducted using simulated GC sessions rather than actual visits (Roter et al. 2007; Lea et al. 2011).

Practice implications

Expanded testing criteria, healthcare reform, and reduced costs have made counseling and testing accessible for many more patients of LHL, LEP, and diverse cultural backgrounds. Going forward, the All of Us Research Program and other NIH initiatives that require inclusion of diverse populations in genomic research will expose broad segments of the US population to genomic medicine. Although inequities in the utilization of cancer genetic testing persist (Armstrong et al. 2005; Levy et al. 2011; McCarthy et al. 2016; Olaya et al. 2009; Pal et al. 2014), studies show that there is interest in genetic services among diverse populations (Komenaka et al. 2016; Ramirez et al. 2015; Ricker et al. 2006). For Chinese immigrant patients to reap the full benefits of GC/GT, effective communication with GCs is essential.

GCs can improve the communication process by enhancing their capacity to draw out Chinese patients' existing beliefs about the causes of cancer, cancer management, and family communication and then incorporate the educational information in a nonjudgmental manner (Barlow-Stewart et al. 2006). Our team has also developed a pre-counseling educational video to introduce Cantonese-speaking patients to genetic counseling, genetic testing, screening/prevention options for HBOC and Lynch syndrome, and the importance of family communication. Adapted from a video our team created earlier for English and Spanish speakers (Joseph et al. 2010), this 12-min video tells the story of 38-year-old Chinese woman diagnosed with breast cancer and an HBOC mutation from her perspective and can be viewed immediately prior to counseling in the clinical setting or at home with family. In addition, we have developed a training curriculum for healthcare interpreters in cancer genetics (Lara-Otero et al. 2016; Roat et al. 2016) to support interpreters' continuing education in the field of genetics.

To support counselors, we have begun to adapt evidenced-based communication strategies for limited literacy patients (e.g., Coleman 2011; Schillinger et al. 2003; Sudore and Schillinger 2009; Brega et al. 2015; Fagerlin et al. 2011; Nouri and Rudd 2015) to the cancer GC context and to test the feasibility of their implementation. Given the findings of numerous studies regarding the literacy demand of genetic counseling and poor retention of information conveyed during

genetic counseling (Roter et al. 2007; Meiser et al. 2008; Paul et al. 2015), it is worth considering the extent to which our findings might be relevant for all patients, not just those of limited literacy. Only 12% of the US population has proficient health literacy, meaning that they can complete tasks such as calculating an employee's share of health insurance costs using a table (Kutner et al. 2006; Nielsen-Bohlman et al. 2004). Furthermore, health information and the healthcare system can be difficult for highly skilled people for a variety of reasons, including the complexity of information presentation, use of unfamiliar scientific and medical jargon, demands of navigating the healthcare system, such as locating providers and services and filling out forms. Perhaps most important for the genetic counseling setting, people of all literacy levels have difficulty understanding information when facing a new diagnosis or a stressful medical situation (Kutner et al. 2006; USDHHS 2010). As such, the Agency for Healthcare Research and Quality (AHRQ) suggests using a "Health Literacy Universal Precautions Approach" to making health information and healthcare contexts accessible for everyone (Brega et al. 2015; DeWalt et al. 2011). This approach incorporates the principle of using plain language. As Stableford and Mettger (2007) explain, the use of plain language, which also has been endorsed by international bodies (WHO, European Commission), is "not about "dumbing down" information, writing in a condescending tone, or neglecting the need for accuracy" (p.79). Rather, it is about clarity and meaning in written and oral communication.

Conclusion

Understanding the mechanisms of inheritance and the implications of genetic test results can be challenging for anyone, and it is exceptionally daunting for those who have LEP and/or low literacy. Research such as ours, on current GC practices with patients of LEP and diverse cultural backgrounds, has important implications for ensuring that disparities do not widen as genomic medicine reaches a more diverse population. As the field of cancer prevention and treatment moves toward the practice of precision medicine, more evidence-based strategies and interventions are needed to effectively engage diverse patients of different cultural backgrounds, language proficiencies, and literacy levels in conversations about genetics, heredity, and disease risk.

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Compliance with ethical standards

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

Human subjects 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.

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