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Medical Interpreter-Mediated Genetic Counseling for Spanish Preferring Adults at Risk for a Hereditary Cancer Syndrome

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Author contributions. GJ and CG confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Compliance with Ethical Standards

Conflict of Interest

GJ, CG, NML, CH, LSK, MJG, JZ, BR, MK, LR, TLK, ML, BW declare that they have no conflict of interest.

Human Studies and Informed Consent

Approval to conduct this human subjects research was obtained by the Kaiser Permanente Northwest IRB (Protocol #000733).

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. Informed consent was obtained from all participants included in the study.

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

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Abstract

The objective of this study was to identify interpretation challenges specific to exome sequencing and errors of potential clinical significance in the context of genetic counseling for adults at risk for a hereditary cancer syndrome. Thirty transcripts of interpreter-mediated telephone results disclosure genetic counseling appointments were coded for errors by bilingual researchers, and the coders applied an overall rating to denote the degree to which the errors interfered with communication overall. Genetic counselors reviewed a subset of errors flagged for potential clinical significance to identify those likely to have clinical impact. Qualitative interviews with 19 interpreters were analyzed to elucidate the challenges they face in interpreting for genetic counseling appointments. Our analysis identified common interpretation errors such as raising the register, omissions, and additions. Further, we found errors specific to genetic counseling concepts and content that appeared to impact the ability of the genetic counselor to accurately assess risk. These errors also may have impacted the patient's ability to understand their results, access appropriate follow-up care, and communicate with family members. Among interpreters' strengths was the use of requests for clarification; in fact, even more use of clarification would have been beneficial in these encounters. Qualitative interviews surfaced challenges stemming from the structure of interpreter work, such as switching from medical and non-medical interpretations without substantial breaks. Importantly, while errors were frequent, most did not impede communication overall, and most were not likely to impact clinical care. Nevertheless, potentially clinically impactful errors in communication of genetics concepts may contribute to inequitable care for limited English proficient patients and suggest that additional training in genetics and specialization in healthcare may be warranted. In addition, training for genetic counselors and guidance for patients in working effectively with interpreters could enhance interpreters' transmission of complex genetic concepts.

Keywords

medical interpreters; health care interpreters; Hispanic; Latino; genetic counseling; exome sequencing; limited english proficiency (LEP); language access

1. INTRODUCTION

With over 62 million people, Hispanics/Latinos make up 19% of the United States (US) population and are among the fastest-growing segments of the population (Pew Research Center, 2021). They continue to face significant disparities in access to and utilization of health care (Artiga et al., 2020), including poorer health insurance coverage (Agency for Healthcare Research and Quality, 2019), quality of care, cancer screening (Fiscella & Sanders, 2016), and genetic counseling and testing (Cragun et al., 2017; Jagsi et al., 2015). Immigration status (Cabral & Cuevas, 2020; Rodríguez et al., 2009), limited health literacy (Becerra et al., 2017), educational attainment (Howe Hasanali et al., 2016), and limited English proficiency (Becerra et al., 2017; Gulati & Hur, 2022) are also barriers to care.

Almost 30% of US Hispanics/Latinos aged 5 years (~20 million people) report speaking English less than “very well” and thus may have limited English proficiency (LEP) (U.S. Census Bureau, 2020). Among Hispanics/Latinos, having LEP has been shown to be associated with lower rates of colorectal cancer screening (Liss & Baker, 2014), and cervical cancer screening (Braschi et al., 2014), and receiving less health education and having lower satisfaction with medical providers (Ngo-Metzger et al., 2007) than Hispanics who are English proficient.

The Affordable Care Act (U.S. Department of Health and Human Services, n.d.) requires medical entities to provide LEP patients with “qualified” medical interpreters. There are currently two organizations that provide a national certification process for medical/healthcare interpreters (InterpreterEd.com, 2021); they are similar in terms of the required minimum education of high school or equivalent, and 40 hours of interpreter training. However, there are no federal regulations that require interpreters to be certified, and the factors to determine qualification, including level of fluency, training, and competency, are often vague and at the discretion of individual institutions, private companies, or states (Jacobs et al., 2018).

Studies of interpretation quality in a variety of clinical settings have found frequent errors of interpretation of moderate to high clinical significance depending on modality of interpretation and whether interpreters are trained professionals or ad hoc such as family or untrained bilingual staff (Nápoles et al., 2015). Professional interpretation has been shown to improve care processes and outcomes (Karliner et al., 2007). Research has also shown that professional interpreters make fewer errors than ad hoc interpreters and communicate more effectively overall (Flores et al., 2012; Gany et al., 2010; Nápoles et al., 2015; Silva et al., 2016). Furthermore, Flores and colleagues (2012) found that among professional interpreters, the number of hours of interpreter training, but not years of experience, were significantly associated with the number, type, and potential clinical significance of errors.

As the Spanish-speaking LEP population in the US gains access to genomic testing and sequencing in a wide range of clinical and research settings, the need for effective interpreter-mediated genetic counseling is increasing, yet little is known about the quality of interpretation in genetic/genomic medicine. Initial studies suggest that interpreters have

limited knowledge, understanding, training, and experience with genetics and genomics (Gutierrez et al., 2017; Joseph & Guerra, 2015; Lara-Otero et al., 2019; Riddle et al., 2022; Uebergang et al., 2021). Given the complexity of genomic medicine, and the communication challenges even in language concordant discussions of genetics (Joseph et al., 2017, 2022), the objective of this study was to identify interpretation challenges and clinically significant errors specific to exome sequencing in order to identify training needs for interpreters and genetic counselors, with the goal of improving communication and health equity for LEP patients in genomic medicine.

2. METHODS

2.1 Study Design

The CHARM study ([NCT 03426878](#)) is one of seven projects in the Clinical Sequencing Evidence-Generating Research (CSER) consortium, which prioritized engagement of populations historically underrepresented in genomics research and underserved in clinical genetics, including those with LEP (Amendola et al., 2018). The overall goal of CHARM was to streamline the cancer genomic service process through a series of interventions to enhance accessibility for a diverse English- and Spanish-speaking adult patient population (Mittendorf et al., 2021).

Patient participants in CHARM (age 18–49) were identified from primary care settings at two integrated health systems: Kaiser Permanente Northwest (KPNW) in the Portland, Oregon, metropolitan area, and Denver Health (DH), a safety net system in Denver County, Colorado. Patients were eligible if they were at elevated hereditary cancer syndrome risk based on study-adapted risk assessment tools for hereditary breast and ovarian cancer syndrome and Lynch syndrome or had unknown risk because of limited family history knowledge (Mittendorf et al., 2021, 2022). Participants submitted a saliva sample for clinical exome sequencing and received results related to hereditary cancer risk, medically actionable secondary findings (optional), and carrier risk (optional). All genetic counseling results disclosure appointments were conducted by telephone and audio recorded (Mittendorf et al., 2021).

The interpreter study within CHARM had three components. The first was development and evaluation of a two-hour exome sequencing training for interpreters, with 24 interpreters randomized to receive the training before or after completing two interpretations for CHARM. In evaluating the effectiveness of the training, Riddle et al (2022) found that interpreter confidence increased, but there was not a significant improvement in interpreter genetics knowledge and concluded that additional time to raise and discuss interpreters' questions during the training was needed. The second component, reported here, consisted of an error analysis of interpreter-mediated genetic counseling sessions for a subset of the CHARM study population who had a medical interpreter present for their results disclosure appointment. The third component consisted of qualitative interviews with the 24 interpreters to explore their experience with the training (reported in Riddle 2022) and their experiences interpreting (reported here).

2.2 Interpreter recruitment

We collaborated with a private interpreter company which provides on-demand audio interpreter services to Kaiser Permanente Northwest and thus to the CHARM study, to recruit interpreters for participation in our study. It is a large provider of on-demand interpretation in many languages for healthcare and other organizations in the US. The company provides training and continuing education for interpreters. We provided a training manager at the company with a recruitment invitation email to send to eligible Spanish-English interpreters. Eligibility criteria included: being a bilingual Spanish interpreter, a Medical Specialized Interpreter, indicated by completion of the company's training and proficiency testing in clinical-medical interpretation; meeting expectations on the most recent company quality assurance observations; having a good attendance record; planning to stay in their job for the next year; and working a shift that overlapped with hours of the CHARM study's results disclosure appointments. Prior experience interpreting for genetics was not required. Once 24 eligible interpreters consented to participate, we stopped recruiting.

2.3 Data collection

Data for this analysis consists of transcripts of genetic counseling sessions, qualitative interviews, an interpreter questionnaire, and the CHARM baseline patient survey (Mittendorf et al., 2021). Genetic counseling sessions with enrolled interpreters occurred over an 11-month period (July 2019-May 2020), were conducted by the four genetic counselors in the CHARM study, and were audio recorded. Of the 63 sessions completed by the 24 interpreters, 30 were selected for analysis using the following criteria: distribution of test results to roughly match those in the CHARM study overall - pathogenic/likely pathogenic (n=2), variant of uncertain significance (n=4), pathogenic carrier (n=1), and normal (n=23); an equal number from trained and untrained interpreter arms; an equal number of first and second CHARM appointments for the interpreter (each interpreter completed two); all four CHARM genetic counselors. These 30 ended up including 19 of the 24 interpreters. The counseling sessions were transcribed verbatim by professional Spanish/English bilingual transcribers and the transcription was checked for accuracy by a Spanish/English bilingual research associate.

We conducted semi-structured qualitative interviews with the 24 interpreters after they had completed their interpretations for the study. The purpose of these interviews was to understand their experience with CHARM interpretations and training and their overall experience as interpreters (Riddle et al., 2022). Interviews were conducted outside of work hours and in the interpreters' preferred language by language concordant interviewers. Most (21/24) were conducted in English and were transcribed (and translated as needed) for coding and analysis. Interviews lasted 40–60 minutes and participants received a \$25 gift card. Interpreter demographic and other characteristics were collected via the pre-post training questionnaires (Riddle et al., 2022).

2.4 Data analysis

Descriptive statistics were used to detail patient and interpreter characteristics.

Counseling session transcript error identification—Three bilingual team members (CG, CH, and NML) identified errors and performed an overall assessment of the impact of the errors on the communication. CG is a masters-level bilingual research associate with extensive training and experience with research on genetic counseling communication and interpretation quality in cancer genetics; CH is a bilingual genetic counseling assistant who was trained in qualitative research methods and coding for this study; NML is a doctoral-level behavioral intervention and patient communication scholar, who is also a certified translator with over 35 years' experience in translation and interpretation for various national and international scientific organizations and government agencies. LK, a physician-investigator expert in language access and interpretation in clinical care, provided guidance at the beginning of the analytic process for setting up the codebook and the overall assessment framework and was consulted at regular intervals throughout the analytic and writing process. GJ, an expert in qualitative methods and a scholar of genetic counseling communication, oversaw the analytic process.

The three bilingual team members read the transcripts and met biweekly to discuss and identify interpretation errors and challenges posed by the communication styles of patients or genetic counselors. As there is no standard method for evaluating errors or their clinical significance, we developed an initial set of codes based on this initial transcript review and a literature review (Cox et al., 2019; Flores et al., 2012; Laws et al., 2004; Nápoles et al., 2015). The codebook evolved iteratively with further coding, and changes made were applied to transcripts coded earlier in the process. We coded for types of interpretation errors including omission, substitution, incorrect, convoluted, and register change up or down. Register is the way a speaker uses language in different circumstances, and is distinguished by sophistication in vocabulary, complexity of grammar and syntax, use of specialized vocabulary, and turns of phrase. In interpretation, errors in register occur when the level of formality, choices of grammatical structure, or other lexical elements do not correspond to the original utterance. In addition, we coded interpreters' strategies to enhance the interpretation (e.g. requests for clarification from patient or genetic counselor) and coded the section of the genetic counseling appointment during which the errors occurred (e.g. family history discussion, explanation of test results) (McCarthy Veach et al., 2018). All transcripts were coded by at least two coders with discrepancies resolved by consensus. In addition, NML and GJ were consulted when the coders had questions about specific excerpts and to resolve discrepancies. We used Dedoose (version 8.3.47), a qualitative data analysis software program to code the transcripts.

Potential impact of errors on clinical care—After each transcript was coded, coders wrote a comprehensive summary, including examples of representative errors, the sections of the session during which they occurred, and any additional elements that impeded or limited effective communication, such as poor audio connection, background noise, or patient distraction. Then, using an overall rating scale ranging from 1 'errors in interpretation prohibited communication or led to major misunderstanding/miscommunication' to 5 'few or no errors in interpretation or errors did not impede communication' (adapted from (Diamond et al., 2022)), coders by consensus added their assessment of whether and how much errors impeded communication. We also used this overall rating to assess whether

there was a difference in the quality of communication by interpreters who had undergone the genetics training vs. those who had not yet undergone the training. Finally, two genetic counselors reviewed the examples of representative errors which were flagged by the coders as having potential clinical significance and rated them for impact on clinical care and/or patient understanding (Yes, Maybe, or No).

Interpreter interviews—For the purposes of this study, we include analysis of the 19 interpreters whose sessions we analyzed for errors. Interpreter interview transcripts were coded using a content analysis approach. Four coders participated, with each transcript coded by two coders using Dedoose; discrepancies were resolved by consensus. For this report, we reviewed and summarized coded data relevant to interpretation quality including: prior training and background, experience interpreting for genetics, genetic counselor-patient communication, perceptions of their own skills, perception of patients, genetic counselor behaviors that helped the interpretation, and suggestions for genetic counselors when working with interpreters. Coded data and emerging themes were discussed with the full analysis team (GJ, CG, NL, MC).

3. RESULTS

3.1 Participants

All interpreters identified as female and as Hispanic or Latina. Only one had heard of exome sequencing prior to participating in the study. Other demographic information for interpreters is presented in Table 1. Patients whose sessions were analyzed for this study identified as Hispanic or Latino, selected Spanish as their preferred language, and requested interpretation. Other patient characteristics are presented in Table 2. The 30 results disclosure sessions had a mean length of 40 minutes ranging from 18 to 71 minutes.

3.2 Error identification

3.2.1 Types of errors identified most frequently

Change in register: The interpreters consistently increased the register (e.g., sophistication in vocabulary, complexity of grammar and syntax, use of specialized vocabulary, and turns of phrase) of both the patient's and the genetic counselor's speech. Changes in register can obscure the speaker's intent, for example, leading the genetic counselor to think the patient has a higher literacy level, thus possibly skipping explanations or not using an appropriately low register. Changes in register can also alter the flow of the conversation; an erroneous higher register can make it difficult for the patient to understand, and as a result, they may request clarification or feel overwhelmed and tune out. The genetic counselors participating in the CHARM study strived to use plain, everyday language to make their communication accessible to participants of all literacy levels (Joseph et al., 2022; Mittendorf et al., 2021). However, interpreters frequently raised their register, inadvertently undoing the genetic counselor's efforts to make their speech more accessible, and potentially making it more difficult for patients of limited health literacy to understand (Table 4, ex 2).

Omissions and additions: Minor omissions, consisting of a single word or emotive utterances, were most common, e.g., interpreting 'breast cancer' as 'cancer', or omitting

the word ‘genetic’ when interpreting ‘genetic test results.’ Occasionally major omissions occurred, which included the omission or summary of entire sentences, leaving out important details. These major omissions mostly occurred during the discussion of family history or the explanation of exome sequencing results. In one instance (Table 3, ex 2) the patient was trying to describe a cancer treatment her grandmother had undergone. This interpreter omission left out important details about a family member’s cancer treatment that genetic counselors often use to gauge the stage or type of cancer that is important to their risk assessment. Errors of addition occur when interpreters add a word, phrase, or segment of speech, altering what the clinician or patient originally states. As with omissions, these could be minor or major. Some interpretations contained both omissions and additions as in one case where the interpreter omitted the concept of actionable secondary finding category of results and added the concept of predisposition (Table 5, ex 2).

Incorrect interpretation: We found incorrect interpretations involving both medical and non-medical terms. For example, in one instance, the interpreter misconstrued a key message, saying the patient needed additional genetic testing when the genetic counselor said no further testing was needed. In other cases, the interpreter used a false cognate, such as translating the Spanish term ‘pendiente’ (which means ‘to be alert’) as “pending”. (Table 5, ex. 6 and 3.)

Convoluting language: Convoluting language was frequent and could make it difficult to understand what the interpreter was saying. This appeared to occur most often when the interpreter did not understand a concept or vocabulary, or when the genetic counselor or patient spoke in long segments. In such cases, the interpreter sometimes also summarized or translated too freely leading to errors of omission and addition, or to confusion.

3.2.2 Errors related to Genetics Concepts and Terminology

Family history: Frequently, errors during the family history discussion involved commonly used rather than technical terms, with interpreters misstating the gender of some relatives (e.g., grandfather vs. grandmother), or failing to clarify that a non-gender-specific term such as “siblings” (*hermanos*) can refer to both brothers and sisters or just brothers. Relatively common English terms or expressions (e.g., ‘blood relative,’ ‘family tree’, or ‘illnesses that run in families’) appeared to cause substantial problems for interpreters, resulting in the use of convoluted or incorrect language, omissions, or additions. Errors also arose during the frequently awkward part of the risk assessment when the genetic counselor asks if there is a chance that the mother and father are blood related (Table 3, ex. 1.) Occasionally, we observed interpreters struggling to follow the patient narrative, especially in cases of patients with large families, or patients who did not narrate in a linear fashion or did not respond directly to the genetic counselor’s questions.

In several instances the interpreters added questions that the genetic counselors had not asked, leaving the genetic counselor out of the conversation, and potentially impeding an accurate risk assessment. On one occasion when a genetic counselor asked about paternal grandparents, the interpreter asked about paternal *and* maternal grandparents, and in another case, when the genetic counselor asked how many siblings the father had, the interpreter

asked how many siblings the father *and* the mother had. Furthermore, the added questions sometimes yielded information that the interpreter followed-up on with additional questions, again without including the genetic counselor.

Risk and heredity: In several cases, we observed interpreters who appeared to be struggling to understand the concepts of genetic risk and heredity, which made it difficult to correctly interpret. In some cases, they requested clarification, but this did not always resolve the problem (Table 4, ex 3). In addition, terms such as ‘chance’, which genetic counselors often used in place of ‘risk’ to make it easier to understand for patients with lower health literacy, and concepts such as predisposition, often resulted in interpreters raising the register (Table 4, ex. 2 and 5).

The concept of heredity also proved challenging for some interpreters. Discussions involving the concept of heredity included explanations of “conditions that can be passed to children” and illnesses, diseases, conditions or health problems that “run in families.” In many cases, the interpretations became convoluted and involved incorrect use of words or phrases. (Table 4, ex 5.)

Results disclosure: Disclosing clinical exome sequencing results in the CHARM study typically involved two or three categories of results (cancer, secondary or “other medically actionable health problems,” and carrier screening results) that added complexity to the interpretation. We found that interpreters sometimes omitted key details as the counselor reminded the patient of the types of results the patient had opted to receive, as well as during disclosure of the outcomes of each (i.e., pathogenic, normal, or VUS). Furthermore, though counselors in CHARM frequently tried to simplify their genetic terminology, interpreters did not always follow suit. Simple phrases such as “problems that we tested you for,” “genetic cause,” or “a gene has an error” were often interpreted in a higher register. For example, one CHARM genetic counselor frequently referred to deleterious variants as “bad changes in the gene” in an effort to use lay language. One interpreter changed this to “malignant gene, malignant mutation,” while another changed it to “some improper function,” thereby interfering with the genetic counselor’s intent to make this information accessible. Discussions of screening and other follow up care recommendations frequently included omissions, summarizing, or incorrect translation of medical terms, as shown in Table 5.

3.2.3 Interpreters’ efforts to enhance communication—We documented some instances in which it appeared that the interpreter intended to enhance communication, by simplifying the genetic counselor’s speech (lowering the register), or adding or changing words in a way that appeared to be an attempt at “cultural brokering” or communicating emotional support or empathy. For example, in one instance, when the genetic counselor mentioned “breast MRI” the interpreter added “what we call a magnetic resonance for the breasts or an MRI” in an apparent attempt to clarify a term that she did not expect the patient to know. The most common technique for enhancing communication was requesting clarification or for the speaker to use shorter utterances. Almost all the interpreters requested clarification at least once, though the response did not always fully clarify the speech adequately.

3.2.3 Overall assessment of how much errors impeded communication—

Using our overall communication rating scale of 1–5, our coders rated 20 of 30 sessions as level 3 or 4, indicating that communication was only “somewhat” or “a little” impeded despite containing many errors. In eight of the sessions, the errors impeded communication a lot (level 2) and in two, the errors led to major misunderstanding or miscommunication (level 1). (See Supplementary Table 1.) In one of the level 1 sessions, the ability of the interpreter to perform effectively was compromised by both the patient and genetic counselor speaking in especially long segments throughout the session; the interpreter did ask for clarification one time, but did not request shorter segments. We found no association between the rated level and either type of results or whether the interpreter had undergone our training prior to the session.

3.2.4 Potential Clinical Impact of Errors—Overall, genetic counselors found that among the errors flagged by coders as potentially clinically significant, those most likely to impact clinical care occurred during risk assessment or were errors that prevented patients from understanding the counselor’s key messages about the meaning of their test results. Among the errors that impeded an accurate risk assessment to a degree that could impact clinical care (see Table 4) were examples such as interpreting the term “blood relatives” as “distant relatives,” preventing an accurate assessment of consanguinity; omission of the patient’s description of her relative’s cancer treatment; and changing the location of a relative’s primary cancer.

Other potentially clinically significant errors involved the patient’s ability to understand the genetic counselor’s key messages, such as that pathogenic *BRCA1/2* variants convey cancer risk or whether the patient needed further genetic testing. In such cases, while we were unable to determine the patient’s understanding, it was clear that the error distorted the message, and patient misunderstanding could have prevented the patient from acting appropriately on their cancer risk or communicating it accurately to their potentially at-risk family members.

Other key concepts that were miscommunicated or omitted and may have had a clinical impact were complex components of genomic medicine that are difficult to convey in language concordant genetic counseling, let alone through an interpreter. This included residual risk, clinically actionable results, multiple categories of test results emerging from a single exome sequencing test, and the difference between screening and diagnostic testing.

3.2.5 Qualitative interviews with interpreters—When asked about the challenges faced in their work overall or specifically in genetics, the interpreters noted a variety of barriers to accurate interpretation. Lack of familiarity was clearly an issue. Only one of the interpreters had heard of exome sequencing prior to the CHARM study. Some interpreters mentioned that not having the opportunity to interpret for genetics more often (e.g., long lag between CHARM appointments and relatively few other genetics appointments) made it harder to remember concepts and vocabulary. Interpreters reported that it was helpful when the genetic counselors in CHARM offered the interpreter a brief explanation of what to expect regarding the structure and content at the beginning of the session. Other barriers interpreters reported experiencing in general (not just in CHARM) included technical issues

(e.g., difficulty hearing the speakers, inability to see what was going on), and particularities of patient or provider speech (e.g., different accents in English, quick pace of speech, failure to enunciate, and fluctuating volume of speech).

When asked about the structure of their work, interpreters reported doing 20–40 interpretations in a typical eight-hour shift (from home and or a call center) with little time—often less than a minute—between calls. These calls included a range of content, from customer service calls for insurance companies and banks to medical appointments of all kinds, with no advance notice of what they would encounter. As this interpreter described, it could be challenging to switch gears:

...I'm doing a call for, let's say, [the bank] and I have like three different disclosures that are like about a page and a half long about if this were to happen and this, the bank reserves the right to do this... So, I'm in that frame of mind. And then I jump into the CHARM study, and I got to start readjusting gears because it's like, okay, okay, okay. Now you're in a medical field, genealogy... You have to be given some time to be able to switch gears ...you can know all the terms in the world, but you just came from another world. [SPI-03]

Despite these challenges, interpreters generally rated themselves highly, saying they felt the interpretations went well, and they did not appear to be fully aware of the frequency and impact of the errors we documented during their sessions.

The interpreters consistently described their role as a conduit, wherein they could not change what the genetic counselor or patient said, intervene in any way, or provide opinions. They reported that instead, if the patient did not seem to understand or if something the genetic counselor or the patient said was not clear, then they would request clarification or repetition. Interpreters also reported asking genetic counselors and patients to speak in shorter segments to facilitate faithful interpretation. As one interpreter stated

If I did not understand, I have to say something. I can't just keep that doubt to myself. I can't interpret something that I'm not sure what they meant of the statement.

Most interpreters said they felt very comfortable asking for clarification, and we found that most interpreters requested clarification at least once during each session, and a few did so more than once. Nevertheless, some reported looking up unfamiliar terms on google translate and other web resources during the appointment rather than asking for clarification. A couple of interpreters admitted that in some circumstances, it was difficult to request repetition or clarification.

I feel more comfortable with certain doctors and nurses. Because some people aren't in such a rush and they're— you can tell that they want to help the patient. That's where I ask the question directly to the doctor. Other times, if I see someone who's not open, who just wants to get it over with, I prefer to use the dictionary if I need a term. [SPI-07]

Patient speech could be particularly challenging. As one interpreter said, “patients sometimes use very colloquial words to their geographical place and you stop and like [ask], ‘What is that?’” [SPI-022] Another described:

Because most of the LEPs, they speak – it’s hard to understand what they’re saying ‘cause they don’t speak in full sentences most of the time. So, you have to figure out what they’re saying because they don’t have a – I don’t know why, but they don’t have a structure of their sentences. They just kind of say things, you know, and you kind of have to put it together. [SPI-011]

In rare cases, interpreters reported that they would indirectly ask for clarification on behalf of the patient who was clearly not understanding.

But sometimes there has been occasions where I can tell that a person who speaks Spanish really are like just saying yes just like okay, sure. Like they have no clue. And so sometimes I explain that to the English-speaking person like, you know, I think – it’s really streamlined because again, we’re not allowed to give our opinion, obviously, ‘cause you’re just interpreting. But sometimes, you know, you have to kind of say, “You know what, I think they’re not understanding or it’s too complicated,” and so a lot of times doctors or whatever, they appreciate and then they just kind of break it down more, or terms. [SPI-02]

Despite primarily seeing themselves as conduits, several interpreters acknowledged sometimes needing to bridge or broker cultural differences and that providing cultural context for specific words or concepts seemed necessary to translate the meaning. For example, interpreters stated that many Spanish-speaking patients consider cancer a “definite death sentence,” they believe that they will get cancer if they talk about it, or that they are very “reserved” or sometimes afraid to discuss personal issues. Thus, the sensitivity of certain topics could also influence how an interpreter approached the interpretation, as described here:

...encounters that can be a bit challenging when you are giving someone this sort of news regarding, you know, genetic information, or in the case of pediatrics, things that can be going on with your unborn child, and how you handle that with the different culture, it can make the difference between some, a patient listening to you and being open to certain things, or a patient simply shutting down and not willing to listen. [SPI-09]

In other cases, interpreters described avoiding idiomatic expressions or metaphors that don’t translate well (which we observed in the transcripts).

You know, like if you said, you know, it’s raining cats and then you’re not going to say it’s raining cats, you’re going to say it’s raining too much.... it’s those things, as when you have changed the interpretation as far as – that’s like the cultural thing. You know, like you can use phrases or something but yeah, other than that, you’re really interpreting exactly what each other is saying. [SPI-02]

4. DISCUSSION

Similar to other interpreter error analyses in various fields of medicine (Cox et al., 2019; Flores et al., 2012; Gany et al., 2010; Nápoles et al., 2015), we found common errors such as omissions, additions, and incorrect interpretations with varying degrees of clinical significance and impact on patient understanding. The frequency with which interpreters raised the register, which other error analyses have not documented, was notable especially given the effort of CHARM genetic counselors to make their communication accessible to patient participants of lower health literacy. Errors in the register can change meaning, convey to the genetic counselor that the patient has a higher health literacy than is the case, and change the flow of the conversation. Although the clinical significance of such errors was difficult to definitively determine in this study, raising the register can impact the patient's ability to understand their condition and thus follow-up appropriately, and could make it more difficult for the genetic counselor to accurately assess and convey risk. We cannot say why interpreters raised the register so frequently, thus further research on this issue is warranted.

In addition to common errors, our study identified specific genetic concepts and components of genetic counseling that were particularly challenging for medical interpreters. Genetic concepts such as risk, heredity, consanguinity, and clinically actionable test results, multiple categories of test results emerging from a single exome sequencing test, and the difference between screening and diagnostic testing, which are difficult even in language concordant genetic counseling, were especially challenging to interpret. The nuances of genetic counselors' detailed risk assessment during pedigree construction were sometimes lost in translation, especially when patients had large families or complex medical histories. Common terms can in effect become technical in the genetics context, e.g., blood relative or family tree. Interpreters sometimes added questions that the genetic counselor did not ask or failed to clarify the sex or generation of a relative, leading to errors that were more serious in the genetics context than it might have been in other medical settings, given the role of family history in risk assessment, testing decisions, and follow up care recommendations. Errors made in the risk assessment thus could affect subsequent parts of the discussion and impact clinical care.

We also observed that the patient or genetic counselor often forgot the request to speak in shorter segments, and interpreters rarely repeated their request; in some instances, it would have required constant requests for clarification or reminders to shorten their speech segments, which would have disrupted the conversational flow. In other instances, the request for clarification did not result in sufficient clarity for the interpreter and thus errors ensued. Further, interactional dynamics including the power differential between genetic counselors (and other medical providers) and healthcare interpreters, as well as interpreters' work structure (back to back interpretations, cognitive demand of switching between topics and interpreting for unfamiliar subjects) may make repeated interruptions and requests difficult (Brisset et al., 2013).

While some research on medical interpretation has focused on error analyses, other research has explored other components of interpreters' roles in rendering communication, including

bridging cultural differences, conveying empathy and other emotions, and interpreting patient centered dialogue (Krystallidou et al., 2020; Roter et al., 2020; Sleptsova et al., 2014; Theys et al., 2020). Research on such topics has emerged within genetics in recent years (Gutierrez et al., 2019; Wang et al., 2022). For example, Gutierrez and colleagues identified empathic tools that interpreters used to bridge the divide between LEP patients and their genetic counselors in the pediatric cancer genetic setting, though their study focused on clinic-based interpreters with more experience and knowledge of the specific subfield of medicine in which they were working. While some of those bridging tools could be technically conceived as errors (from the conduit perspective), they may have actually improved the communication, or the experience for the patients (Gutierrez et al., 2019). It is clear from our interviews with interpreters that they have been trained to act as conduits, and intend to adhere to that approach except in rare circumstances. In practice, we identified some instances where they (consciously or unconsciously) seemed to attempt cultural bridging, by omitting idiomatic expressions or analogies that do not have meaningful direct translations or words like cancer that may have been perceived as upsetting to patients. Nevertheless, when interpreters change the original emphasis in utterances of patients or genetic counselors, the understanding of, and reaction to, information received by patients and genetic counselors may be affected. For example, minimizing a patient's level of fear about cancer, or the level of cancer risk reported by a genetic counselor could have negative consequences in terms of patient-genetic counselor rapport and trust, or patient adherence to recommendations.

Interpreters' descriptions of their professional experiences overall, as well as their experience interpreting for the CHARM study, adds to a growing body of research that explores interpreters' perspectives on their role and their experiences in practice (Lor et al., 2022; Price et al., 2012), including in genetic counseling (Lara-Otero et al., 2019). Some research has identified a preference for in-person interpretation by both GCs and interpreters (Wang et al., 2022). Yet, the trend in the profession of interpretation is for remote interpreters who do not specialize in a particular field of medicine, or even in healthcare, as in the CHARM study. While remote interpretation increases access for all languages and reduces response time (Karliner, 2017; Pathak et al., 2021), it may also have disadvantages for the interpreters and on interpretation quality, though research is equivocal (Marshall et al., 2019). Our interview findings indicated that interpreters' felt their proficiency was limited by the infrequency of genetics appointments to develop skills and remember vocabulary. This aligns with the result of our interpreter training study, in which we found that the training significantly increased interpreters' confidence, but not knowledge (Riddle et al., 2022).

4.1 Limitations

While our analytic process drew on the literature and prior experience and expertise of the researchers, there is no standard process for assessing interpreters and interpretation errors, and further research is needed to establish best practices. It is possible that the interpreters' participation in the CHARM study (i.e., knowing that they were being recorded and their interpretation studied) may have influenced how they interpreted. The genetic counseling in CHARM was more narrowly focused than in regular clinical care; these sessions

were intended as one-time appointments to disclose test results, confirm family history information, and make recommendations for the patient and their family members. Further, the CHARM study emphasized the use of plain language in all interactions with patient participants given the effort to include those who are historically medically underserved or underrepresented in research. Thus, despite the errors we identified, the CHARM genetic counselors may have used less jargon and scientific explanations than what interpreters would typically encounter.

4.2 Conclusion

Despite major improvements in the access to medical interpreters and the professionalization of the interpreter workforce in recent decades, our findings suggest there is still room for improvement. The rapidly growing field of genomic medicine, and efforts like CHARM to ensure inclusion of diverse patients/participants in clinical genomics and genomic research, means that we will need a cadre of interpreters well-versed in genetic concepts and vocabulary to accurately interpret for genetic counselors and other genetics providers. Efforts should also be made to diversify the genetic counselor workforce to include a larger number of fully bilingual counselors.

4.3 Practice implications

One key implication of our research is that genetic counselors should approach a session with an interpreter with intention. This can include orienting the interpreter to the session, encouraging the interpreter to ask for clarification as needed, using plain language, and asking the interpreter to follow suit. In addition, genetic counselors should limit the use of idioms, analogies, and metaphors when working with interpreters. Other tactics genetic counselors can consider to enhance the proficiency of the interpreters include: speaking in short segments and reminding the patient to do so as well; referring to the patient and family members by their names to help them follow the narrative when discussing family history; letting the interpreter know when the genetic counselor is trying to verify patient understanding (Agency for Healthcare Research and Quality, 2020; Minnesota Health Literacy Partnership, 2012) (e.g using teach back); providing context as to why a question is being asked, for example, explaining that the genetic counselor needs a detailed family history in order to accurately assess risk and make care recommendations. All of these suggestions should be incorporated into formal training through genetic counseling programs or continuing education activities and credit. In addition, bilingual counselors should be offered opportunities to enhance their preparation to counsel in languages other than English. As with other clinical providers, it may be necessary to implement language proficiency testing for those who wish to practice in a language other than English.

To address the need for medical interpreters' proficiency in fundamental genetics and genomics concepts and vocabulary, specialized training could improve overall performance and reduce errors. Our team has created an in-depth course (8 hours over 2 days) that builds on findings described here as well as on the results of our interpreter training study (Riddle et al., 2022). It is available via the HealthCare Interpreters Network (HCIN), where other continuing education classes and workshops funded by the American College of Medical Genetics are also available, to enhance interpreters' understanding of genetic/genomic

medicine (Health Care Interpreter Network, n.d.). Interpreters' employers should provide time and support for interpreters to take such classes. Employers should also consider structuring their interpreter workforce to enable interpreters to specialize in healthcare, allowing them to become topical experts and to reduce the mental burden of switching between topics as different as customer service for banks and genomic medicine and recovery time between calls.

Mutual understanding between genetic counselors and interpreters about their roles, intentions and challenges may serve to improve collaboration and meet the needs of limited English proficient patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability Statement.

The data that support the findings of this study are available upon reasonable request from the corresponding author.

References

- Agency for Healthcare Research and Quality. (2019). 2018 National Healthcare Quality and Disparities Report. <https://www.ahrq.gov/research/findings/nhqdr/nhqdr18/index.html>
- Agency for Healthcare Research and Quality. (2020). AHRQ Health Literacy Universal Precautions Toolkit. <https://www.ahrq.gov/health-literacy/improve/precautions/index.html>
- Amendola LM, Berg JS, Horowitz CR, Angelo F, Bensen JT, Biesecker BB, Biesecker LG, Cooper GM, East K, Filipowski K, Fullerton SM, Gelb BD, Goddard KAB, Hailu B, Hart R, Hassmiller-Lich K, Joseph G, Kenny EE, Koenig BA, ... Jarvik GP. (2018). The Clinical Sequencing Evidence-Generating Research Consortium: Integrating genomic sequencing in diverse and medically underserved populations. *American Journal of Human Genetics*, 103(3), 319–327. PubMed. 10.1016/j.ajhg.2018.08.007 [PubMed: 30193136]
- Artiga S, Orgera K, & Pham O. (2020). Disparities in Health and Health Care: Five Key Questions and Answers. 13.
- Becerra BJ, Arias D, & Becerra MB. (2017). Low health literacy among immigrant Hispanics. *Journal of Racial and Ethnic Health Disparities*, 4(3), 480–483. 10.1007/s40615-016-0249-5 [PubMed: 27324821]
- Braschi CD, Sly JR, Singh S, Villagra C, & Jandorf L. (2014). Increasing Colonoscopy Screening for Latino Americans Through a Patient Navigation Model: A Randomized Clinical Trial. *Journal of Immigrant and Minority Health*, 16(5), 934–940. 10.1007/s10903-013-9848-y [PubMed: 23736964]
- Brisset C, Leanza Y, & Laforest K. (2013). Working with interpreters in health care: A systematic review and meta-ethnography of qualitative studies. *Patient Education and Counseling*, 91(2), 131–140. 10.1016/j.pec.2012.11.008 [PubMed: 23246426]

- Cabral J, & Cuevas AG. (2020). Health Inequities Among Latinos/Hispanics: Documentation Status as a Determinant of Health. *Journal of Racial and Ethnic Health Disparities*, 7(5), 874–879. 10.1007/s40615-020-00710-0 [PubMed: 32026286]
- Cox A, Rosenberg E, Thommeret-Carrière A-S, Huyghens L, Humblé P, & Leanza Y. (2019). Using patient companions as interpreters in the Emergency Department: An interdisciplinary quantitative and qualitative assessment. *Patient Education and Counseling*, 102(8), 1439–1445. 10.1016/j.pec.2019.03.004 [PubMed: 30929764]
- Cragun D, Weidner A, Lewis C, Bonner D, Kim J, Vadaparampil ST, & Pal T. (2017). Racial disparities in BRCA testing and cancer risk management across a population-based sample of young breast cancer survivors. *Cancer*, 123(13), 2497–2505. 10.1002/cncr.30621 [PubMed: 28182268]
- Diamond LC, Gregorich SE, Karliner L, González J, Pérez-Cordón C, Iniguez R, Figueroa JA, Izquierdo K, & Ortega P. (2022). Development of a Tool to Assess Medical Oral Language Proficiency. *Academic Medicine*. 10.1097/ACM.0000000000004942
- Fiscella K, & Sanders MR. (2016). Racial and Ethnic Disparities in the Quality of Health Care. *Annual Review of Public Health*, 37(1), 375–394. 10.1146/annurev-publhealth-032315-021439
- Flores G, Abreu M, Barone CP, Bachur R, & Lin H. (2012). Errors of Medical Interpretation and Their Potential Clinical Consequences: A Comparison of Professional Versus Ad Hoc Versus No Interpreters. *Annals of Emergency Medicine*, 60(5), 545–553. 10.1016/j.annemergmed.2012.01.025 [PubMed: 22424655]
- Gany FM, Gonzalez CJ, Basu G, Hasan A, Mukherjee D, Datta M, & Changrani J. (2010). Reducing Clinical Errors in Cancer Education: Interpreter Training. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 25(4), 560–564. 10.1007/s13187-010-0107-9 [PubMed: 20390395]
- Gulati RK, & Hur K. (2022). Association Between Limited English Proficiency and Healthcare Access and Utilization in California. *Journal of Immigrant and Minority Health*, 24(1), 95–101. 10.1007/s10903-021-01224-5 [PubMed: 34097162]
- Gutierrez AM, Robinson JO, Statham EE, Scollon S, Bergstrom KL, Slashinski MJ, Parsons DW, Plon SE, McGuire AL, & Street RL. (2017). Portero versus portador: Spanish interpretation of genomic terminology during whole exome sequencing results disclosure. *Personalized Medicine*, 14(6), 503–514. 10.2217/pme-2017-0040 [PubMed: 29749861]
- Gutierrez AM, Statham EE, Robinson JO, Slashinski MJ, Scollon S, Bergstrom KL, Street RL, Parsons DW, Plon SE, & McGuire AL. (2019). Agents of empathy: How medical interpreters bridge sociocultural gaps in genomic sequencing disclosures with Spanish-speaking families. *Patient Education and Counseling*, 102(5), 895–901. 10.1016/j.pec.2018.12.012 [PubMed: 30581014]
- Health Care Interpreter Network. (n.d.). HCIN Learn. <https://www.hcinlearn.org/>
- Howe Hasanali S, De Jong GF, & Roempke Graefe D. (2016). Hispanic-Asian Immigrant Inequality in Perceived Medical Need and Access to Regular Physician Care. *Journal of Immigrant and Minority Health*, 18(1), 219–227. 10.1007/s10903-014-0137-1 [PubMed: 25420782]
- InterpreterEd.com. (2021). Interpreter Certifications Compared. <https://interpretered.com/about-us/interpreter-certifications-compared/#content>
- Jacobs B, Ryan AM, Henrichs KS, & Weiss BD. (2018). Medical Interpreters in Outpatient Practice. *The Annals of Family Medicine*, 16(1), 70. 10.1370/afm.2154 [PubMed: 29311179]
- Jagsi R, Griffith K, Kurian A, Morrow M, Hamilton A, Graff J, Katz S, & Hawley S. (2015). Concerns about cancer risk and experiences with genetic testing in a diverse population of patients with breast cancer. *Journal of Clinical Oncology*, 33(14), 1584–1591. [PubMed: 25847940]
- 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. 10.1007/s12687-014-0202-4 [PubMed: 25148879]
- Joseph G, Leo MC, Riddle L, Guerra C, Amendola LM, Gilmore MJ, Rolf BA, Dorschner MO, Zepp J, Biesecker BB, Caruncho M, Hunter JE, Keast E, Lewis HS, Duenas D, Kauffman T, Bulkley JE, Anderson KP, Jarvik GP, ... CHARM Study Team. (2022). An accessible, relational, inclusive, and actionable (ARIA) model of genetic counseling compared with usual care: Results

- of a randomized controlled trial. *Genetics in Medicine: Official Journal of the American College of Medical Genetics*, 24(11), 2228–2239. 10.1016/j.gim.2022.07.025 [PubMed: 36053287]
- Joseph G, Pasick RJ, Schillinger D, Luce J, Guerra C, & Cheng JKY. (2017). Information Mismatch: Cancer Risk Counseling with Diverse Underserved Patients. *Journal of Genetic Counseling*, 26(5), 1090–1104. 10.1007/s10897-017-0089-4 [PubMed: 28289853]
- Karliner LS. (2017). Providing Health Care in the Context of Language Barriers. In Jacobs EA & Diamond LC (Eds.), *International Perspectives* (pp. 20–34). *Multilingual Matters*. 10.21832/9781783097777-004
- Karliner LS, Jacobs EA, Chen AH, & Mutha S. (2007). Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. *Health Services Research*, 42(2), 727–754. 10.1111/j.1475-6773.2006.00629.x [PubMed: 17362215]
- Krystallidou D, Bylund CL, & Pype P. (2020). The professional interpreter's effect on empathic communication in medical consultations: A qualitative analysis of interaction. *Patient Education and Counseling*, 103(3), 521–529. 10.1016/j.pec.2019.09.027 [PubMed: 31623946]
- Lara-Otero K, Weil J, Guerra C, Cheng JKY, Youngblom J, & Joseph G. (2019). Genetic Counselor and Healthcare Interpreter Perspectives on the Role of Interpreters in Cancer Genetic Counseling. *Health Communication*, 34(13), 1608–1618. 10.1080/10410236.2018.1514684 [PubMed: 30230379]
- Laws MB, Heckscher R, Mayo SJ, Li W, & Wilson IB. (2004). A New Method for Evaluating the Quality of Medical Interpretation. *Medical Care*, 42(1), 71–80. [PubMed: 14713741]
- Liss DT, & Baker DW. (2014). Understanding Current Racial/Ethnic Disparities in Colorectal Cancer Screening in the United States: The Contribution of Socioeconomic Status and Access to Care. *American Journal of Preventive Medicine*, 46(3), 228–236. 10.1016/j.amepre.2013.10.023 [PubMed: 24512861]
- Lor M, Badenoch N, & Yang MJ. (2022). Technical Meets Traditional: Language, Culture, and the Challenges Faced by Hmong Medical Interpreters. *Journal of Transcultural Nursing*, 33(1), 96–104. 10.1177/10436596211039553 [PubMed: 34404302]
- Marshall LC, Zaki A, Duarte M, Nicolas A, Roan J, Colby AF, Noyes AL, & Flores G. (2019). Promoting Effective Communication with Limited English Proficient Families: Implementation of Video Remote Interpreting as Part of a Comprehensive Language Services Program in a Children's Hospital. *Joint Commission Journal on Quality and Patient Safety*, 45(7), 509–516. 10.1016/j.jcjq.2019.04.001 [PubMed: 31133535]
- McCarthy Veach P, LeRoy BS, & Callanan NP. (2018). Structuring Genetic Counseling Sessions: Initiating, Contracting, Ending, and Referral. In McCarthy Veach P, LeRoy BS, & Callanan NP (Eds.), *Facilitating the Genetic Counseling Process: Practice-Based Skills* (pp. 139–172). Springer International Publishing. 10.1007/978-3-319-74799-6_6
- Minnesota Health Literacy Partnership. (2012). Teach-Back: What does your patient really understand? <https://healthliteracymn.org/sites/default/files/images/files/Teach-Back%20Program%20Guide.pdf>
- Mittendorf KF, Kauffman TL, Amendola LM, Anderson KP, Biesecker BB, Dorschner MO, Duenas DM, Eubanks DJ, Feigelson HS, Gilmore MJ, Hunter JE, Joseph G, Kraft SA, Lee SSJ, Leo MC, Liles EG, Lindberg NM, Muessig KR, Okuyama S, ... Goddard KAB. (2021). Cancer Health Assessments Reaching Many (CHARM): A clinical trial assessing a multimodal cancer genetics services delivery program and its impact on diverse populations. *Contemp Clin Trials*, 106, 106432. 10.1016/j.cct.2021.106432 [PubMed: 33984519]
- Mittendorf KF, Ukaegbu C, Gilmore MJ, Lindberg NM, Kauffman TL, Eubanks DJ, Shuster E, Allen J, McMullen C, Feigelson HS, Anderson KP, Leo MC, Hunter JE, Sasaki SO, Zepp JM, Syngal S, Wilfond BS, & Goddard KAB. (2022). Adaptation and early implementation of the PREDiction model for gene mutations (PREMM(5)™) for lynch syndrome risk assessment in a diverse population. *Familial Cancer*, 21(2), 167–180. 10.1007/s10689-021-00243-3 [PubMed: 33754278]
- Nápoles AM, Santoyo-Olsson J, Karliner LS, Gregorich SE, & Pérez-Stable EJ. (2015). Inaccurate Language Interpretation and Its Clinical Significance in the Medical Encounters of Spanish-speaking Latinos. *Medical Care*, 53(11), 940–947. 10.1097/MLR.0000000000000422 [PubMed: 26465121]

- Ngo-Metzger Q, Sorkin DH, Phillips RS, Greenfield S, Massagli MP, Clarridge B, & Kaplan SH. (2007). Providing High-Quality Care for Limited English Proficient Patients: The Importance of Language Concordance and Interpreter Use. *Journal of General Internal Medicine*, 22(2), 324–330. 10.1007/s11606-007-0340-z [PubMed: 17957419]
- Pathak S, Gregorich SE, Diamond LC, Mutha S, Seto E, Livaudais-Toman J, & Karliner L. (2021). Patient perspectives on the quality of professional interpretation: Results from LASI study. *Journal of General Internal Medicine*, 1–6. 10.1007/s11606-020-06491-w
- Pew Research Center. (2021). U.S. Hispanic population reached more than 62 million in 2020. https://www.pewresearch.org/ft_2021-09-09_keyfactslatinos_01/
- Price EL, Pérez-Stable EJ, Nickleach D, López M, & Karliner LS. (2012). Interpreter perspectives of in-person, telephonic, and videoconferencing medical interpretation in clinical encounters. *Patient Education and Counseling*, 87(2), 226–232. 10.1016/j.pec.2011.08.006 [PubMed: 21930360]
- Riddle L, Karliner LS, Livaudais-Toman J, Guerra C, Roat CE, Rope AF, Wade A, Caruncho M, Zepp JM, Giang J, Wilfond BS, & Joseph G. (2022). Development and evaluation of an exome sequencing training course for medical interpreters. *Personalized Medicine*, 19(2), 125–138. 10.2217/pme-2021-0091 [PubMed: 35171038]
- Rodríguez MA, Vargas Bustamante A, & Ang A. (2009). Perceived Quality of Care, Receipt of Preventive Care, and Usual Source of Health Care Among Undocumented and Other Latinos. *Journal of General Internal Medicine*, 24(3), 508. 10.1007/s11606-009-1098-2 [PubMed: 19841999]
- Roter DL, Gregorich SE, Diamond L, Livaudais-Toman J, Kaplan C, Pathak S, & Karliner L. (2020). Loss of patient centeredness in interpreter-mediated primary care visits. *Patient Education and Counseling*, 103(11), 2244–2251. 10.1016/j.pec.2020.07.028 [PubMed: 32819755]
- Silva MD, Genoff M, Zaballa A, Jewell S, Stabler S, Gany FM, & Diamond LC. (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. 10.1016/j.jpainsymman.2015.10.011 [PubMed: 26549596]
- Sleptsova M, Hofer G, Morina N, & Langewitz W. (2014). The Role of the Health Care Interpreter in a Clinical Setting—A Narrative Review. *Journal of Community Health Nursing*, 31(3), 167–184. 10.1080/07370016.2014.926682 [PubMed: 25051322]
- Theys L, Krystallidou D, Salaets H, Wermuth C, & Pype P. (2020). Emotion work in interpreter-mediated consultations: A systematic literature review. *Patient Educ Couns*, 103(1), 33–43. 10.1016/j.pec.2019.08.006 [PubMed: 31431309]
- Uebergang E, Best S, de Silva MG, & Finlay K. (2021). Understanding genomic health information: How to meet the needs of the culturally and linguistically diverse community—a mixed methods study. *Journal of Community Genetics*, 12(4), 549–557. 10.1007/s12687-021-00537-0 [PubMed: 34185265]
- U.S. Census Bureau. (2020). Race and Ethnicity in the United States: 2010 Census and 2020 Census. <https://www.census.gov/library/visualizations/interactive/race-and-ethnicity-in-the-united-state-2010-and-2020-census.html>
- U.S. Department of Health and Human Services. (n.d.). Section 1557: Ensuring Meaningful Access for Individuals with Limited English Proficiency. <https://www.hhs.gov/civil-rights/for-individuals/section-1557/fs-limited-english-proficiency/index.html>
- Wang M, Rosenbaum M, Dineen R, Stoll J, Schmitz K, & Hsu M. (2022). Exploring United States genetic counselor and healthcare interpreter perspectives: Allocation of roles within the genetic counseling encounter. *Journal of Genetic Counseling*, 31(4), 976–988. 10.1002/jgc4.1572 [PubMed: 35416393]

1. **What is known about this topic:** Professional medical interpreters facilitate access to genetic counseling for limited English speakers, but tend to have limited knowledge, training, and experience with genetics and genomics.
2. **What this paper adds to the topic:** This study offers new knowledge on the genetics-specific challenges interpreters face, the most common errors they make, and how genetic counselors can collaborate with interpreters to enhance communication with limited English speakers.

Table 1.

Interpreter Characteristics (n=19)

		N (%)
Age	mean (SD)	44.1 (11.6)
	Min-Max	25–71 years
	<hr/>	
Country of Birth	United States	6 (32%)
	Other ^a	13 (68%)
	<hr/>	
If foreign born, how many years have you lived in the U.S.?	mean (SD)	23.9 (14.3)
	Min-Max	2–49 years
	<hr/>	
What is the highest level of education you have completed?	High school graduate or less	3 (16%)
	Some post-high school training	6 (32%)
	College graduate or higher	10 (53%)
	<hr/>	
What is your job status?	Work full-time	11 (58%)
	Work part-time	5 (26%)
	Work more than one job	2 (11%)
	Prefer not to answer	1 (5%)
	<hr/>	
How much experience do you have interpreting for medical appointments where genetic testing is part of the discussion?	No experience	7 (37%)
	A little experience	5 (26%)
	Some experience	7 (37%)
	<hr/>	
How many years have you worked as a medical interpreter?	mean (SD)	4.0 (4.7)
	Min-Max	<1–20 years
	<hr/>	

^aMexico=9; Panama=1; Ecuador=1; Dominican Republic=1; Cuba=1

Table 2.

Patient Participant Characteristics (N=30)

	N ^a	%
Age at risk assessment mean (SD)	39.6 (6.4)	
Gender identity		
Female	25	83
Male	3	10
Education level		
Less than high school graduate	22	73
High school graduate or equivalent	1	3
Some post-HS training or Associate degree	5	17
Health literacy ^c		
Inadequate (4–11)	6	20
Marginal (12–15)	5	17
Adequate (16–20)	17	57
Low-income (<200% Federal Poverty Level)		
No	4	13
Yes	23	77
Housing insecure		
No	22	73
Yes	6	20
Food insecure		
No	23	77
Yes	6	20
Cancer genetic result		
Pathogenic/Likely Pathogenic	1	3
VUS	4	13
Normal	25	83
Additional finding genetic result ^b		
Pathogenic/Likely Pathogenic	2	7
Normal	27	90
Results not requested	1	3

^aMissing includes participants who did not take the CHARM baseline survey or skipped the relevant question.

^bAdditional findings included 77 noncancer, medically actionable secondary finding genes (Amendola 2022)

^cThe measures for health literacy, housing insecurity and food insecurity are explained and cited in the CHARM protocol paper (Mittendorf et al 2021)

Table 3.

Family History Discussions

Ex. #	Concept	Examples	Errors	Potential for clinical impact and rationale
1	Consanguinity	<p><i>Genetic Counselor:</i> Any chance that your mom and dad were related to each other at all by blood?</p> <p><i>Interpreter:</i> ¿Alguna posibilidad de que sus papás sean familiares lejanos?</p> <p><i>* Back translation:</i> Any possibility that your parents may be distant relatives? [RD_1001119]</p>	Incorrect	<p>Yes. <i>May impact risk assessment which in turn can impact clinical recommendations for patient and family.</i></p> <p>Rationale: "Related by blood" interpreted as "distant relative" thereby losing the concept of consanguinity. This question could be interpreted as ONLY distant relatives being important.</p>
2	Building the pedigree/ identifying relatives' illness or cancer treatment/ stage	<p><i>Patient:</i> Bueno, pero mi abuela no falleció de eso. Mi abuela tuvo en la matriz, creo cáncer en la matriz porque la quemaban con —era eso lo que me cuentan, no? Como con rayas, sí, algo así como... no sé cómo se dice, si es cáncer de la matriz....</p> <p><i>Interpreter:</i> Oh, I'm not sure, it was my mom's mom. I don't know if she died from that, but I know she had, I think cancer in her womb.</p> <p><i>* Author translation:</i> Well, but my grandmother did not die from that. My grandmother had [it] in her womb, I think cancer in the womb because she was burned with —that's what I'm told, no? Like with rays, yes, something like with rays, yes, something like... I don't know what it's called, if it's cancer of the womb... [RD_1001257]</p>	Omission	<p>Yes. <i>Treatment information may impact risk assessment which in turn can impact clinical recommendations for patient and family.</i></p> <p>Rationale: Cancer treatment (perhaps radiation) omitted.</p>
3	Building the pedigree/ identifying relatives' illness or stage of cancer	<p><i>Patient [answering if she knew what type of cancer her maternal grandfather had]:</i> No, te digo que también investigué pero tampoco me supieron decir. Pero él tenía cáncer del estómago y del hígado —esófago y el hígado. Le afectó el hígado y el estómago —todo el esófago y pues ya no tuvo cura....</p> <p><i>Interpreter:</i> No, you see as a matter of fact I've been trying to research and nothing, they just tell me that it was cancer. He had cancer in his esophagus, stomach, and liver. Apparently, it started in his liver and went all the way up, so that they could not fix it....</p> <p><i>Author translation:</i> No, I'm telling you that I also inquired but they also couldn't tell me. But he had cancer of the stomach and liver —esophagus and liver. It affected the liver and stomach, all the esophagus, and there was no cure... [RD_1001267]</p>	Addition	<p>Yes. <i>May impact risk assessment and clinical recommendations.</i></p> <p>Rationale: Location of primary cancer (liver vs. GI) can influence risk assessment.</p>

* While acknowledging that in most cases there is often not a single way to translate a sentence, we strove to remain faithful not only to the content, but to the register used in the original source when we provided translations (of the original segment in Spanish into English) and back translations (of the Interpreter's Spanish translation, back into the original source English). All translations and back translations were conducted by the bilingual authors.

Table 4.

Discussions Involving the Concepts of Risk and Heredity

Ex.	Concept	Examples	Errors	Potential for clinical impact and rationale
1	Explanation of Risk associated with BRCA genes	<p><i>Genetic counselor:</i> the <i>BRCA1</i> and the <i>BRCA2</i> genes are genes that actually help -- they're, they're related to breast cancer risk and ovarian cancer risk.</p> <p><i>Interpreter:</i> El <i>BARC1</i> y el <i>BARC2</i> (sic) son genes que están relacionados con los genes del seno y del ovario</p> <p><i>Back translation:</i> The <i>BARC1</i> and the <i>BARC2</i> (sic) are genes that are related to the genes of the breast and ovary. [RD_1001296]</p>	<p>Omission</p> <p>Incorrect</p>	<p>Yes. A crucial component and key message of the counseling is that these genes are related to cancer risk.</p> <p>The statement does not convey what is intended: that the <i>BRCA</i> genes are related to a person's cancer risk.</p>
2	Explanation of risk related to a mutation	<p><i>Genetic Counselor:</i> And when those genes have a bad change or a mutation in them that causes them not to work, then a person's chance to get cancer goes up.</p> <p><i>Interpreter:</i> Y cuando este estilo de gene [sic] no están funcionando bien o tienen algún tipo de cambio, de mutación, esto ayudan -- no están funcionando en el cuerpo y las personas que pasan por esto tienen una posibilidad más alta de cáncer.</p> <p><i>Back translation:</i> And when this style of gene are [sic] not functioning well or they have some type of change, of mutation, this they help --they are not functioning in the body and the people who go through this have a higher possibility of cancer. [RD_1001179]</p>	<p>Change in Register Up</p> <p>Convolved</p>	<p>Maybe. <i>May impact patient understanding but won't necessarily have a clinical impact.</i></p> <p>Rationale: Errors do not impact key messages, but could impact patient understanding of hereditary cancer risk</p>
3	Familial Risk due to patient's test results	<p><i>Genetic counselor:</i> Now, the chance for your children or your brothers and sisters or your parents to get colon cancer is a little bit high because you might have some of the same risks in the environment that they have. So, they still need to get earlier screening for cancer. But they don't have the very, very high risk that they would have if there was an inherited gene in the family.</p> <p><i>Interpreter:</i> Muy bien. La probabilidad de que los hijos de usted, sus hermanos o sus padres pudieran desarrollar cáncer de colon es elevada ¿Por qué? Porque, están teniendo los mismos riesgos ambientales en los cuales usted se desarrolló. Entonces es impor... es importante que realicen pruebas, que se realicen estudios más, más temprano para detectar el cáncer. Porque podría ser --</p> <p><i>Back translation:</i> Very well. The probability that your children, your siblings or your parents could develop colon cancer is elevated. Why? Because they are having the same environmental risks in which you developed. So, it is impor.... it is important to conduct tests, that earlier... that earlier tests be conducted to detect cancer. Because it could be...</p> <p><i>Interpreter requesting clarification/</i> sorry madam, the last part regarding the after the screening of -- earlier screening for cancer.</p> <p><i>Genetic counselor:</i> Mm-hm, um, um.</p> <p><i>Interpreter:</i> Higher inheritance?</p> <p><i>Genetic counselor to interpreter:</i> Um, but it's not um as high of a risk as if they had an inherited cause. Is not as if she had an inherited cause of cancer.</p> <p><i>Interpreter:</i> Entonces, a pesar de que, de que sí tienen un nivel elevado de, de riesgo por el -- los mismos -- por, por el mismo ambiente en el cual se están desenvolviendo y que se les recomendó hacerse revisiones tempranas para la detección de cáncer, no es tan elevado pa -- con respecto del riesgo o más bien el riesgo en el que pudieran obtener el cáncer por un tema hereditario no es tan elevado como es el ambiental.</p> <p><i>Back Translation:</i> So, in spite of the fact that you do have an elevated level of... of risk because of the... of the same environment in which you are unfolding and that it's recommended that you get early examinations for</p>	<p>Change in Register Up</p> <p>Convolved</p> <p>[Genetic counselor should speak in shorter segments; interpreter should remind genetic counselor to speak in shorter segments]</p>	<p>Maybe. <i>May impact patient understanding which could influence family members about risk</i></p> <p>Rationale: The interpreter struggles to understand the counselor's detailed and nuanced explanation of genetic and environmental risks in the context of normal genetic test results, and despite appropriately asking for clarification, she struggles to interpret.</p>

Ex.	Concept	Examples	Errors	Potential for clinical impact and rationale
4	Explanation of GC role	<p>cancer detection, it's not that elevated for... with respect to the risk, or rather the risk in which you could obtain cancer due to a hereditary issue, is not as elevated as the environmental one is. [RD_1001220_012320]</p> <p><i>Genetic counselor:</i> "... genetic counselors like me talk to people about health problems that can run in families, so that's why we talk with people in the CHARM study about their test results."</p> <p><i>Interpreter:</i> Los consejeros genéticos somos personas que hablamos con las -- con ustedes acerca de los posibles problemas que existen en la familia, aunque pudieran habl -- aparecen en la familia por este estudio.</p> <p><i>Back translation:</i> Genetic counselors are people who talk with the -- with you about the possible problems that exist in the family, although they could... they appear in the family, through this study. [RD_1001267]</p>	Convoluted	No. Rationale: While unclear, and the patient may not understand the counselor's explanation of her role, it is unlikely to affect clinical care.
5	Explanation of inherited conditions	<p><i>Genetic counselor:</i> Now, the good news is that we looked at many genes that can cause colon cancer and can be passed in the family, and we did not find any changes in genes that could cause an inherited kind of colon cancer.</p> <p><i>Interpreter:</i> Las buenas noticias es que nosotros estudiamos varios genes que pueden ocasionar cáncer de colon y que pueden ser transferidos a lo largo de su línea familiar. Y también le vemos algunos otros con -- que pueden producir cambios que no necesariamente son heredados de una persona a otra.</p> <p><i>Back translation:</i> The good news is that we studied several genes that can engender colon cancer and that can be transferred along your family line. And we also see in you some others with... that can produce changes that are not necessarily inherited from one person to another. [RD_1001220]</p>	Convoluted Change in Register Up Addition	Maybe. <i>May impact patient understanding of and thus ability to act on the test result.</i> Rationale: Concern about addition of the concept of genetic changes not inherited from one person to another.
6	Residual risk	<p><i>Genetic Counselor:</i> Oh, you're welcome. And so, the main thing that I want you to take away from this conversation is that all of your testing came back normal which is really good news, um, but, you know, still go to your doctor. Like you said, if you feel like something is off, um, follow up with your doctor, make sure you still, um, do what they recommend, like, for example, your mammograms and things like that, um, because genetic tests can't tell us everything right? So, you still have a chance -- a small chance of these health problems happening just like everyone else does, but you are doing all the right things to take care of yourself.</p> <p><i>Interpreter:</i> Pues sí, señora, sí en verdad y pues bueno creo el, el punto primordial que se puede usted llevar de esta conversación es que todos sus estudios genéticos resultaron normales y esas son muy buenas noticias. Pero de todas maneras vaya con su doctor, sígale dando seguimiento y siga -- y si usted aún siente como que puede obtener un beneficio, un -- una mayor información, siga en comunicación y vea -- porque todas estas cosas que usted está realizando, este, preventivamente, también nos habla a nosotros acerca de, de como podemos afrontar, eh, un futuro si algo sucede. O sea, no podemos evitar que a un -- en algún futuro suceda algo, pero estamos mejor preparados para enfrentarlo.</p> <p><i>Back translation:</i> Well, yes, ma'am, yes, it's true and so I think the, the most important point that you can take away from this conversation is that all your genetic tests came out normal and that that is good news. But in any event, go to your doctor, continue your follow-up and continue -- and if you still feel that you could benefit from more information, keep in touch and see -- because all of these things that you are doing, um, preventatively, also tells us about, about how we can face it, uh, if something happens in the future. We can't avoid something from happening in the future, but we can be better prepared to confront it. [RD_1001267]</p>	Omission	Maybe. <i>May impact patient understanding related to residual risk and need to continue cancer screening.</i> Rationale: Key message normal result is interpreted clearly, but concept of residual risk gets lost.

Table 5.

Results Disclosure Discussions

Ex. #	Concept	Examples	Errors	Potential for clinical impact and rationale
1	Explanation of pathogenic result	<p><i>Genetic counselor:</i> “So, everybody has the genes that we tested for, but what we’re looking for is a change in the gene, or what you might call a typo in the letters in the gene”.</p> <p><i>Interpreter:</i> “Okay, entonces todos tenemos el gen, pero lo que nosotros buscamos es la falla en el gen”.</p> <p><i>Back translation:</i> “Okay, so we all have the gene, but what we look for is the fault in the gene”. [RD_1001119]</p>	Omission	<p>No.</p> <p>Rationale: Interpreter conveyed the concept that the test is looking for a fault in the gene, despite omitting the analogy of the typo. Could be an attempt at clarifying analogy/cultural brokering</p>
2	Explanation of “Secondary findings” (Also called “additional findings” or “other health problems”; in CHARM these were findings for clinically actionable non-cancer conditions.)	<p><i>Genetic counselor:</i> We did also do some other genetic testing as part of our study. We did two other kinds of genetic testing; one was to look for genetic changes that would lead to a genetic condition that we might be able to treat.</p> <p><i>Interpreter:</i> Okay señora, entonces, aparte de esta prueba genética del cáncer hicimos para otras pruebas, otra clase de enfermedades, para ver si usted está predispuesta, para ver si hay algún tratamiento que se pueda ofrecer.</p> <p><i>Back translation:</i> So, aside from this genetic test for cancer, we did for other tests, another kind of illnesses, to see if you are predisposed, to see if there is some treatment that can be offered. [RD_1001119]</p>	Omission Addition	<p>Maybe. <i>May impact patient understanding of implications of all test result categories.</i></p> <p>Rationale: Concept of clinically actionable secondary finding category of results was not conveyed, and the concept of predisposition was added.</p>
3	Discussion of follow-up care	<p><i>Patient [describing her doctor as always monitoring her health]:</i> La doctora siempre está pendiente de todo lo que tengo, lo que hago.</p> <p><i>Interpreter:</i> The doctor is always pending on what I need and everything I do. [RD_1001267]</p>	False cognate	<p>No.</p> <p>Rationale: Non-essential context for genetic counselor</p>
4	Discussion of Carrier Results	<p><i>Genetic counselor:</i> So, for that group of result, we do have a test result that we want to talk with you about and it’s related to a chance of your children having hearing loss, so hearing problems</p> <p><i>Interpreter:</i> Entonces los resultados de esa prueba, hay uno que quisiéramos hablar un poquito más, esto es en cuanto a las probabilidades de tener pérdida de audición o problemas en el oído.</p> <p><i>Back translation:</i> So, the results of that test, there’s one that we would like to talk a little more about, and it is about the probabilities of having loss of hearing or problems in hearing. [RD_1001123]</p>	Omission	<p>Yes. <i>The omission of children being at risk impacts the main takeaway related to the inheritance pattern of the carrier results.</i></p> <p>Rationale: Omits of the key point that the problems being described could affect the patient’s children, effectively misconstruing the defining characteristic of carrier screening.</p>
5	Recommendation for follow-up Care	<p><i>Genetic Counselor:</i> And even though there is more uterine cancer than we would expect on that side of the family, there is no good screening for uterine cancer, so I wouldn’t change what your doctor recommends for you.</p> <p><i>Interpreter:</i> Pero como no hay evaluación, alguna evaluación, entonces es muy importante que usted siga todas las recomendaciones que el doctor le da.</p> <p><i>Back translation:</i> But because there is no evaluation, some evaluation, so it’s very important that you follow all the recommendations that your doctor gives you. [RD_1001177]</p>	Omission	<p>Maybe. <i>May impact patient understanding.</i></p> <p>Rationale: Interpreter appears to miss the context related to the uterine cancer in the family, so the “what to do next” is clear, but the “why” is not.</p>
6	Recommendation for follow-up Care	<p><i>Genetic Counselor:</i> So, I don’t think any more genetic testing for health conditions in you, like I said, makes sense.</p>	Incorrect	<p>Yes. <i>Likely impacts patient understanding of key message that additional genetic testing is not indicated at this time.</i></p>

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Ex. #	Concept	Examples	Errors	<i>Potential for clinical impact and rationale</i>
		<p><i>Interpreter:</i> Entonces yo creo que sea necesario un examen genético de nuevo para enfermedades que haya en usted ahorita.</p> <p><i>Back translation:</i> So, I think it is necessary to do a genetic test again for illnesses that may be in you right now. [RD_1001126]</p>		<p>Rationale: The interpreter says the opposite of what the GC said.</p>