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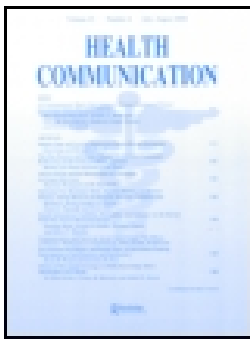
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Genetic Counselor and Healthcare Interpreter Perspectives on the Role of Interpreters in Cancer Genetic Counseling

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ABSTRACT

Cancer genetic counseling (CGC) combines psychosocial counseling and genetic education provided by genetic counselors to patients and families who have a history of cancer and are considering or have undergone genetic testing for hereditary cancer syndromes. The quantity and complexity of information provided can be challenging for any patient, but is even more so for those with limited English proficiency (LEP). This exploratory study investigated healthcare interpreters' and genetic counselors' perspectives on the role of interpreters in providing care to LEP patients during CGC. Through a survey of 18 interpreters and conventional content analysis of semi-structured interviews with 11 interpreters and 10 GCs at two California public hospitals, we found that: 1) interpreters viewed their role as patient advocate, cultural broker, and emotional support, not simply a conduit; 2) interpreters were challenged by remote interpretation, lack of genetic knowledge, and the emotional content of encounters; 3) interpreters and GCs held conflicting views of the value of counselors' limited Spanish knowledge; and 4) trust, the foundation of the interpreter-provider dyad, was often lacking. The challenges identified here may result in poor healthcare experiences and outcomes for LEP patients. As genomics becomes more widespread and more LEP patients encounter CGC, the role of healthcare interpreters in facilitating effective communication must be further defined in order to facilitate better working relationships between interpreters and genetic counselors, and optimal communication experiences for patients.

KEYWORDS

Limited English proficiency (LEP); health literacy; health communication; patient-provider communication; health disparities; healthcare interpreters; genetic counseling; cancer; hereditary cancer; inter-professional communication

Introduction

Cancer genetic counseling (CGC) combines psychosocial counseling and genetic education provided by genetic counselors (GCs) to patients and families who have a history of cancer and who are considering or who have undergone genetic testing for hereditary cancer syndromes (Butow & Lobb, 2004). Given the quantity and complexity of the information provided in the traditional Genetic Counseling (GC) model (Berliner, Fay, Cummings, Burnett, & Tillmanns, 2013), CGC can be challenging for any patient, but even more so for those with limited English proficiency (LEP). LEP refers to having a limited ability to read, write, speak, or understand English (Title VI of the Civil Rights Act of 1964; Policy guidance on the prohibition against national origin discrimination as it affects persons with limited English proficiency, 2000), and is a significant barrier to accessing health services and to medical comprehension (Jacobs, Karavolos, Rathouz, Ferris, & Powell, 2005). Furthermore, LEP has been shown to contribute to poor health communication and consequently to disparities in both healthcare utilization and health outcomes (Jacobs et al., 2005; Kim et al., 2011). Limited health literacy (LHL) is defined as having a limited capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2000).

The combination of LHL and LEP is synergistic (Rudd, 2007; Sudore et al., 2009), so LHL among LEP patients can limit communication effectiveness and understanding even when a professional healthcare interpreter (HI) is involved. LHL is thought to affect about 8 million US adults (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011) and is more common among LEP individuals compared to the general population (Sentell & Braun, 2012). Genetic counseling has been shown to have a high literacy demand (Roter, 2011) and to be challenging to patients of limited literacy (Joseph et al., 2017) and LEP (Cheng et al., 2018; Joseph & Guerra, 2015).

The use of professional HIs has proven to be an effective bridge between LEP patients and healthcare providers and has been shown to improve healthcare outcomes (Flores, 2005; Karliner, Jacobs, Chen, & Mutha, 2007). Nevertheless, interpreter-mediated communication adds complexity that warrants further investigation. Existing literature regarding interpreted healthcare encounters suggests that patient-provider communication benefits from a combination of traditional and nontraditional practices to forge an effective working alliance between clinicians and interpreters (Brisset, Leanza, & Laforest, 2013; Guerrero, Small, Schwei, & Jacobs, 2018; Mirza, Harrison, Chang, Salo, & Birman, 2017). For example, Mirza et al. (2017) found that effective communication with refugee patients in the mental healthcare setting was less about interpreters' performance and more about performance of a three-way communication system. Furthermore, the authors

observed that effective communication with LEP patients requires flexibility in communication behavior by all three parties, with clinicians adopting the standard role of addressing potential communication breakdowns, but on occasion (e.g., when working with less experienced interpreters) adopting additional roles to guide and reinforce the interpreter. Similarly, interpreters sometimes were more effective in facilitating patient-provider communication when they deviated from the “language processor” role (Mirza et al., 2017) by avoiding communication mishaps that could have persisted when translating verbatim. In a review of 61 qualitative studies regarding interpreted medical encounters, Brisset et al. (2013) identified three emerging themes: 1) interpreters adopt many roles during medical encounters which can be the source of tension but in some circumstances can provide an opportunity to strengthen the relationship between interpreters, patients, and providers; (2) all parties involved in an interpreted encounter face difficulties associated with issues of “trust, control, and power” (p. 136), and striving for balance among the three would promote better quality of care; and (3) communication characteristics involving nonliteral translation can foster more effective communication between patients and providers. In support of these findings, Leanza et al. (2015) found the main challenge in interpreter-mediated patient-provider communication to be collaboratively building an integrative framework “characterized by trust, recognition of each other’s roles in the encounter, respect, training and active support for both interpreters and clinicians” (p. 367).

In contrast to these empirical findings, professional HIs have been traditionally conceptualized as conduits, a mechanical role consisting of the transfer of information from one language to another neutrally and faithfully. Interpreter-as-conduit is the dominant ideology in both interpreter training programs and interpreter codes of ethics (Dysart-Gale, 2005), and healthcare providers have reported viewing the interpreter as “a neutral ‘translating machine’ that provides services without distorting their voice or compromising the quality of care” (Fatahi, Hellström, Skott, & Mattsson, 2008; Hsieh & Kramer, 2012). However, optimal interpretation involves an array of skills beyond bilingual proficiency including mastery of medical terminology in both languages, superior memory skills, the ability to negotiate a three-way conversation, and basic knowledge of cultural attributes that can influence health (Grantmakers in Health, 2003). Furthermore, studies have demonstrated that the complexity of provider-patient interactions makes the conduit model impractical, if not unrealistic (Angelelli, 2004; Dysart-Gale, 2007). Professional HIs improve care for LEP patients by mediating information exchange between patient and clinician, and by actively participating in the medical encounter, establishing rapport and communicating emotions (Raymond, 2014). Thus, when interpreters deviate from the conduit model in an attempt to provide optimal services, the relationship between provider and interpreter may be jeopardized.

Although there is considerable literature addressing the impact of suboptimal interpretation services on the quality of healthcare in various types of clinical encounters, (e.g., pediatric and emergency room settings), these studies primarily examined the perspectives of clinicians and patients (Flores et al., 2003). Despite their critical role in language discordant

encounters and cross-cultural patient-provider communication, the voice of HIs is surprisingly absent from the literature (Hudelson, 2005). There is little research in genetic counseling concerning the role of HIs, and it largely addresses interpretation as part of a broader account of genetic services for culturally diverse, LEP patient populations (Hunt & De Voogd, 2007; Krieger, Agather, Douglass, Reiser, & Petty, 2018; Saleh, Barlow-Stewart, Meiser, & Muchamore, 2009).

This exploratory study examined the perspectives of both GCs and HIs on CGC sessions conducted with remote (telephone or video) interpreters. This study emerged from clinical observations conducted for a study of CGC communication in two safety net hospitals in large metropolitan areas of California serving ethnically diverse patients, nearly all of whom have Medicaid and Medicare or are uninsured (Joseph et al., 2017). Those observations revealed an uneven quality of interpretation, and challenges for GCs working with LEP patients and interpreters (Cheng et al., 2018; Jacobs et al., 2005; Kamara, Weil, Youngblom, Guerra, & Joseph, 2018). Thus, our primary research questions were: what training and expertise do interpreters bring to the CGC encounter, what are their perspectives on the CGC encounter, and what types of challenges do HIs and GCs perceive in their respective roles and their partnered working relationship during interpreter-mediated CGC encounters? The purpose of the present study was to analyze and compare data reflecting GC and HIs perspectives to examine challenges of providing care to LEP patients in the CGC setting, and to inform strategies to improve the interpretation process, which may be exacerbated by the complexity of genetics as well as remote interpretation. To our knowledge, ours is the first study to explore the experiences and perspectives of interpreters participating in this kind of clinical encounter.

Methods

This mixed method inductive study analyzed semi-structured qualitative interviews with HIs and GCs, and a survey with HIs. The semi-structured interviews with GCs were conducted as part of and during the larger study of CGC communication (2013–2015) (Joseph et al., 2017). The semi-structured interviews and survey with interpreters were conducted as part of an exploratory study carried out while the larger study was being implemented to examine HIs perspectives on CGC communication. All procedures were approved by the University of California, San Francisco Institutional Review Board.

Study participants

GCs were eligible if they were board certified with a Masters in genetic counseling, and had been observed while providing GC services at either of two California safety-net hospitals for the CGC communication study. Interpreters were eligible for the survey if they worked at one of the participating public hospitals, and for an interview if they had experience interpreting during GC appointments of any kind. Some, but not all, had interpreted for counseling appointments observed for the CGC communication study (we could not always identify the interpreter due to remote interpretation and because interpreters did not identify

themselves by name). Interpretation at this hospital was primarily conducted remotely by telephone; video medical interpretation and in-person interpretation were also sometimes used.

Survey

Surveys were distributed during an interpreter staff meeting where the PI explained the study and provided interpreters with an envelope to return the survey confidentially. In addition to demographic characteristics, the 40-question survey included open and closed ended questions about training received (e.g., Have you had any formal training as a medical interpreter? Yes/No); attitudes toward training (e.g., For your work as a medical interpreter, how helpful would it be to have a training on cancer, including specific vocabulary and an opportunity to ask questions? (Not helpful/helpful/extremely helpful); experience interpreting for GCs (e.g., Have you ever interpreted for a genetic counselor (a specialist who discusses family history and inherited conditions)? Yes/No); and challenges of the medical interpreter role (e.g., As a medical interpreter, how challenging is communicating through the telephone for medical interpretation? Very challenging/somewhat challenging/not at all challenging). Verbal consent was obtained, and interpreters who completed the survey received a \$10 gift card.

Qualitative interviews

Semi-structured qualitative interviews with interpreters were conducted in the language preferred by the interpreter (described further below) by a member of the research team. Interviews were conducted in person and lasted between 60 and 90 min. The interview guide aimed to obtain a comprehensive understanding of interpreters' views and perspectives as well as the context of the job; as such interview topics included: personal and professional history, interpreters' role and training, interactions with patients, experiences working with GCs in cancer genetics, as well as experiences with other providers; and remote interpretation by telephone and video, which had become the main modality by which their services were provided.

Semi-structured interviews with participating GCs were conducted in person after several months of clinical observations (Joseph et al., 2017), and lasted approximately 60 min. Interview topics covered a range of subjects including professional history and training, clinic structure, perceptions of and communication with patients specifically with regard to literacy, culture and language, their work with HIs, and specific patient sessions that had been observed.

Written consent was obtained for all the qualitative interviews, and participants were compensated for their time with a \$50 gift card.

Data analysis

Surveys

We used SPSS to calculate frequencies for demographic and other characteristics of the interpreters. Due to the small number of participants ($n = 18$), no other analyses were performed.

Qualitative interviews

All qualitative interviews were digitally recorded, professionally transcribed verbatim and translated to English as needed for analysis. We used Atlas.ti (v7) to code the interview data. Four members of the research team read the interpreter transcripts independently, and then met to compare and discuss initial open coding. After discussing the first few transcripts, we established a codebook which we used to code the remaining transcripts (Miles, Huberman, & Saldana, 2013). The GC interview transcripts were coded by three researchers as part of the analysis for the larger study (Joseph et al., 2017). For the present study, we analyzed a subset of data related to GCs' experience working with interpreters, including data that had been coded as: communication challenges; cross-cultural communication; GCs' strategies with interpreters; GCs' suggestions for training; GCs' perceptions of interpreters' understanding of analogies and of terminology, requests for clarification, and technical difficulties; and use of/failure to use interpreters. When analyzing the two data sets (interpreter and counselor interviews) together, we used conventional content analysis approach (Hsieh & Shannon, 2005), focusing on salient aspects of interpreters' and GCs' work together to serve LEP patients, and to identify the four key themes presented below.

Results

Participant characteristics

Ten Masters level GCs participated in semi-structured interviews. Characteristics of the GCs are presented in Table 1. Years of experience as a genetic counselor ranged from 3 months to 25 years. Eight were White, one was African American, and one was Asian American and White.

Eighteen of 24 (75%) eligible interpreters completed the survey. Interpreters' characteristics are presented in Table 2. Participants had spent an average of 13.2 years (SD 9) working as a healthcare interpreter, but only half had received any training in genetics, and 17/18 reported that it would be extremely helpful or helpful to have additional training in basic genetic concepts (one did not respond to this question). Most were born outside the US but had lived in the US for an average of 29 years. Notably, some interpreters rated their own English proficiency as having only "medium comfort" speaking English ($n = 4$) and understanding English ($n = 3$). While these numbers are small and may not be representative of the interpreter population, this lack of comfort in English may contribute to uneven quality of interpretation. Of the 11 interpreters who agreed to participate in a semi-structured interview, 7 chose to be interviewed in Cantonese or Spanish.

Table 1. Characteristics of the genetic counselors.

Site	Gender	Race/Ethnicity	Years in Practice (range)	Total
1	3 women	3 White	4–25 years	3
2	5 women 2 men	5 White 1 African American 1 Asian American/White	3 months–25 years	7
Total:				10

Table 2. Characteristics of the healthcare interpreters ($n = 18$).

Characteristic	Mean (SD) or n (%)
Age	56.1 (8)
Unreported $n = 5$	
Region of birth	
U.S./Canada	1 (6)
Mexico/Central America	4 (22)
East Asia (including China)	2 (11)
Southeast Asia (including Vietnam)	8 (44)
Eastern Europe	2 (11)
Unreported	1 (6)
Years in the U.S. (born outside U.S. $n = 17$)	29 (12)
Unreported $n = 6$	
Highest level of education in home country (born outside U.S. $n = 17$)	
Elementary	1 (6)
Secondary or high school	3 (18)
Some college	3 (18)
College degree	3 (18)
Professional degree	4 (24)
Unreported	3 (18)
Highest level of education in the U.S.	
Elementary	0
Secondary or high school	0
Some college	6 (33)
College degree	7 (39)
Professional degree	2 (11)
Unreported	3 (17)
Self-rated level of comfort in English: Speaking	
High	12 (67)
Medium	4 (22)
Low	0
Unreported	2 (11)
Self-rated level of comfort in English: Understanding	
High	12 (67)
Medium	3 (17)
Low	0
Unreported	3 (17)
Years as a healthcare interpreter	13.2 (9)
Unreported $n = 3$	

Qualitative analysis results

We identified four themes that represent the perspectives of the interpreters and GCs: 1) interpreters view their role as more than a conduit; 2) interpreters face multiple challenges when working with LEP patients; 3) interpreters and GCs hold conflicting views of the value of GCs limited knowledge of Spanish; and 4) trust is the foundation of the interpreter-provider dyad, but often was lacking. The sample was too small to detect clear patterns specific to Spanish/Latino as compared with Cantonese/Chinese.

Interpreters' role

Interpreters indicated that they were trained to interpret following the conduit model of interpretation where they are expected to transfer information from one language to another neutrally and faithfully. Nevertheless, most participants believed that to serve the patients' best interest, they needed to enact multifaceted roles as patient advocate, cultural broker, and patients' transient emotional support.

Interpreters most frequently identified their role as patient advocate. They almost invariably stated that their primary motivation to become an interpreter was to help LEP patients access the care they need and deserve by bridging educational, socioeconomic, cultural, and other differences between patient and provider.

Interpreter: Well, my role is ... to advocate for the patient. It's also often advocate in the sense that the

[providers] have a cultural understanding of the person, because the cultures are very different, often, from those of the doctor... It's a difference of country, class, way of thinking, language. There are so many things that you... try to work with when you're interpreting so that the patient is treated in the best way possible, with dignity, with respect, with... love. [HI #1]

Interpreters similarly saw their role as bridging potential patient distrust of medical providers or the medical system by providing "reassurance" and "transparency" about the healthcare encounter.

Interpreter: I think just reassurance and facilitator and hopefully transparency so that patients know that everything is out in the open and nothing's being hidden from them ... and the translation is very accurate. [HI #2]

Interpreters also expressed their willingness to take on practical or logistical tasks to help patients navigate the healthcare system, despite discouragement from managers. One interpreter provided examples of going beyond her official role to help ensure that the patient accessed the care she needed.

Interpreter: I think the official role, it's mostly conduit... But I just care for the patients and I often, I mean like I'm not supposed to take somebody's number and say, "Okay, I'll call you in half an hour and we'll call the clinic again and let's see." Or, "Let me try to get this information for you to, I'll call, call you back"... It's not really expected of me, or, maybe it could be even discouraged in some ways, but I just, I just feel bad, you know. [HI #3]

Interpreters took on the role of cultural broker to help the patient and provider bridge sensitive aspects of healthcare and distinct views of health and wellness. In the following case, the interpreter believed it was part of his role to explain specific cultural beliefs to the providers in order to facilitate the communication, particularly in cases where a medical procedure considered routine and harmless in the Western biomedicine (e.g., blood draw) may have a different meaning for a patient with a different cultural background.

Interpreter: There has been a case with a young woman and unmarried, the doctor said, "I'm going to do a pelvic exam for you, so I'm going to look in your cervix to see what's going on." And the patient felt very uneasy, you know, because in our culture, Chinese culture, having a single woman, unmarried, never married before. I mean, they [are] concerned about the hymen, and virginity... [S]o I tell the doctor that, "Look, she never married before. In certain culture, in the old days, they don't want their husband to think that they are not clean." [HI #4]

Another interpreter believed it was important to take into account the strong religious beliefs she saw among many Latino patients that prevent some from grasping commonly discussed topics during a CGC session.

Interpreter: We have people, because they're very religious, they don't believe in random acts. . . Everything that happens has a specific cause. And that doesn't work with genetics. [HI #5]

In these two examples, the interpreters drew on their understanding of patients' cultural beliefs and experiences that they did not expect the provider to have or that they believed might influence the way some patients understood the information provided. In particular, HI #4 considered it important to provide some cultural context for the provider in this context.

The majority of interpreters also described their role as going beyond a simple conduit because they found it challenging to remain unresponsive to patients' suffering, especially when the interpreter was communicating emotionally difficult information or bad news. As the following excerpt reflects, interpreters felt deeply affected by patients' tragic circumstances. In this case, the interpreter expressed her desire to provide emotional support, and the difficulty of doing that when she was on the phone rather than in the room with the patient (discussed further in theme 2).

Interpreter: . . . a patient had come into the Oncology Department with pancreatic cancer and she had been told that it could be treated with chemotherapy and I got to tell her [as the voice of the doctor] over the phone that nope, it can't, and even with chemotherapy you've got a year. Without chemo, you've only got six months. And it just seemed really heartless to be [interpreting] that over the phone. . . "Cause that's where I might have, you know, like given a pat or something." [HI #2]

Interpreters consistently stated that the conduit model of interpretation not only limits the ways in which they can contribute to the provision of culturally appropriate care, but also disregards their potential as a source of emotional support for patients.

Major challenges for interpreters

Interpreters described a range of challenges including technical difficulties associated with remote telephone and video interpretation, their limited knowledge of genetic terminology and concepts, and the emotional aspects of their job.

Remote interpretation services in medical centers serving LEP patients increases access to medical interpretation, in terms of both the number of patients served and the languages available. However, interpreters in our study identified a number of disadvantages of telephone or video interpretation. They expressed significant concerns about conducting lengthy (45–60 min) GC sessions remotely, due to technical difficulties that jeopardize the quality of the interpretation and the

difficulty of interpreting complex and emotional content without nonverbal cues.

Interpreter: [A] few years ago I was interpreting for [GC] and they were talking [about] this BRCA, you know BRCA1, BRCA2, which I, at this point, had never heard of it. And this was [a hospital unit] which really had very poor. . . connection on VMI [Video Medical Interpreting], so you couldn't really hear well. And, there was a patient with, maybe three family members . . . I was so stressed. I couldn't really understand what they were talking about, what the [genetic counselor] was saying, what the [family members] were asking [HI #3].

Interpreters cited background noise in the interpreters' call center and in the exam room (e.g., shuffling papers near the microphone) as frequently contributing to communication problems between the provider and interpreter.

With the advent of phone interpretation interpreters reported having an increased number of interpretations per day, and increased stress due to the volume of calls.

Interpreter: When we got this phone system, we were getting 20–30 calls each day at one point. . . Now, we only get one minute to rest in between calls. . . In the past when it was very busy, one minute of rest was too long. . . Sometimes we put the system on hold to get a drink of water, and there would be a call waiting already. . . Our supervisor does not consider that we may be stressed out. Sometimes, the [providers] give us attitudes, but we just have to suck it up. . . Even now, sometimes we get one minute of rest in between calls. Other times, we get less. [HI #7]

For these interpreters, the remote interpretation work setting and equipment could generate a tremendous amount of stress and anxiety; a situation they believed was largely unrecognized by providers.

Interpreters were acutely aware of their limited knowledge of genetic terminology and limited understanding of basic genetic concepts. As part of the CGC encounter the genetic counselor explains genetics-related concepts (e.g., chromosome, genes, DNA, inheritance patterns) in order to educate the patient on subjects such as hereditary cancer syndromes, genetic testing, surveillance recommendations, prophylactic measures, and treatment options. Some interpreters admitted feeling overwhelmed by the nature and amount of information conveyed to the patient.

Interpreter: As I said, I didn't do well. I think [the patient and her husband] had a lot of questions. . . I mean, I didn't understand it, so how could I really translate it well if I didn't understand the concepts. [HI #1]

Another interpreter described her first time interpreting for a prenatal GC session and how "embarrassing" it was to provide a "poorly" executed interpretation due to her limited command

and understanding of technical terminology. This interpreter's experience reflects the challenge of providing services for specific subspecialties when providers do not use lay language and interpreters do not have specialized training. The importance of the latter was highlighted by the following interpreter:

Interpreter: ...when you're doing an interpretation, it's better if you've studied before...For example, the genes. ...I don't know if it's BRCA1 or, I don't remember the terms, okay, that makes you more likely to get cancer, it doesn't mean you're condemned to get cancer. And you have to know how to say things in such a way that the patient understands what the situation is. [HI #5].

This interpreter, although not certain of the terminology, demonstrated a clear understanding of the concept of risk (i.e., that inheriting a BRCA1 gene mutation does not "condemn" the patient to develop cancer but rather increases the chances of developing cancer). The conceptual understanding portrayed by this interpreter represents a strength without which clear communication is unlikely to be achieved.

Interpreters also discussed the emotional challenges of interpreting CGC sessions. Patients present with complex, sometimes tragic stories, such that discussions can have an emotional impact on everyone involved. GCs are trained to manage this aspect of counseling and are likely to be better prepared to process emotionally loaded cases. In contrast, interpreters do not receive training in how to manage and cope with emotionally complex cases and may face more challenges processing and recovering psychologically from these cases. The following excerpt demonstrates how emotionally difficult discussing bad news can be.

Interpreter: ...you're dealing with a situation where you just want to burst into tears any minute and you can't. You have to be very professional. But then when you leave the room you burst into tears. You know, that kind of stuff. Sometimes you need a little emotional help. [HI #6]

Interpreters' coping strategies for managing difficult cases like these varied. As described in the next quote, one interpreter sought comfort in her faith and in colleagues.

Interpreter: I step away for a minute from the monitor, ... and I go to the chapel to cry for a bit...Or I talk with one of my colleagues. And, I think that my faith, my religion has also helped me a lot... Because praying, asking God to help the patients and to give me the strength to keep going [HI #8].

Another interpreter talked about becoming desensitized to patients' suffering, perhaps as a coping mechanism that he consciously or unconsciously employed to deal with the day-to-day stress of the job.

Interpreter: As interpreters, we sometimes encounter patients that have tragic stories, especially when they are asked to talk about their

terminal illness. They would become very sad and would start crying. For the most part, we are desensitized because we have heard so many stories but once in a while, they stir up emotions in us. [HI #10].

Despite the various challenges associated with their job, some interpreters, like this one, appeared to handle the stresses of the job adequately and maintained a largely positive attitude toward their work.

Conflicting views of counselors' limited knowledge of spanish

Several of the GCs understood and/or could speak some Spanish. From their perspective, this was an added skill that, on some occasions, allowed them to recognize potential misinterpretations of their message or even to conduct the counseling themselves. Although they sometimes relied on their limited Spanish during GC encounters, they also recognized their shortcomings.

Genetic Counselor: I'd say, "Well, no, that's not quite what I said. What I said was" - you know, and I'll rephrase it and try to get the interpreter to say it right. Yeah, and still you don't really know. And I don't know Spanish as a first language so I don't really know what nuances there might be. [GC #1]

The counselors were particularly concerned that the psychosocial assessment and the accuracy of the information they provide could be jeopardized when an interpreter mediates the conversation.

Genetic Counselor: I was trained to be very intentional with my language... [I would say] "Please just say what I just said," and I know that there are words for that in Spanish. ...There's such a strong psychosocial component that it would be like misrepresenting what someone is saying...in a therapy session. [GC #2]

Despite recognizing that their Spanish proficiency is limited, counselors' like this one nevertheless ventured to "correct" the interpreter to minimize the potential loss of critical content.

In contrast, the interpreters did not respond well to being "corrected" by non-fluent Spanish speakers, and they expressed serious reservations about providers' ability to communicate effectively with patients when relying on their limited command of a patient's native language. Interpreters were not only concerned that the provider would miss substantial content but also were distressed when they were asked to present only as backup or midway through a session when the provider recognized that an interpreter was needed.

Interpreter: ...the worst are the [providers] who speak some Spanish... sometimes they use horrible Spanish... I know what he's trying to say

because I know what he's saying, but I'm thinking, does the patient understand it? ... So, whenever they come across the word that they don't know in Spanish, they will just use English. ... [or] the [provider] starts speaking the broken Spanish, and the patient answers him in broken English ... I think it's very nice for the [provider] to be speaking directly to the patient, but they're missing, they're probably missing, let's say, 30%, or 20%. And then suddenly they get stuck because the patient said something that suddenly, like, they don't know what it is. And then they call interpreter ... and you are like in the middle of the conversation... You don't know what they're talking about... I mean, just like give the interpreter really a chance to do their job. [HI #4]

Another interpreter described a situation in which her services had been requested by a provider who expected to conduct the session in Spanish and to have the interpreter available to correct her in case she made a mistake. The conflicting views of interpreters and counselors with regard to counselors' use of limited Spanish knowledge reflects the mistrust between the two groups of providers, as discussed in the next theme.

Lack of trust in the interpreter-provider relationship

Interpreters and GCs consistently mentioned trust as a critical component of the interpreter-provider dynamic. Many interpreters were of the opinion that providers frequently expressed, explicitly or implicitly, distrust in their ability to interpret adequately. This situation often arose when patients provided broad, unspecific answers to the provider's questions due to cultural or educational factors. When this occurred, interpreters tried to negotiate with the patient to answer the provider's specific question leading to a longer exchange between interpreter and patient than the provider expected. As the following excerpt illustrates, such circumstances can lead to feelings of mistrust by GCs and interpreters.

Interpreter: [T]here are [providers] who have questioned us, either because they think they can speak [the patient's language], or because the patient's answer is not what they were expecting, so they think we didn't ... ask the question correctly... One [provider] said to me, "I don't care what you think. I care about what the patient thinks." And I said, "[Provider], I'm just repeating what the patient is saying." So, that they believe me, you know, that they trust the interpreter because I'm not there to take the [provider's] place. I'm there so that communication is better. [HI #8]

As another interpreter put it, "if there is an issue of miscommunication or a language problem, the [provider] tends to blame the interpreters, instead of patients" [HI #4].

In the following example, the interpreter described how she manages situations in which a concept has no linguistic or conceptual equivalent in the other language, and thus requires a longer explanation than the original speech.

Interpreter: [The Provider] said, "I only told you two sentences, short ones. How come you make it up so a long interpretation? What's going on here?"

Interviewer: Oh, so he heard you speak in Cantonese, and obviously, he didn't know what you were saying, so he asked you why you were speaking for so long.

Interpreter: Right. He asked me what I said, and I told him. Because of Chinese culture and the questions that providers are asking, I can't always interpret word for word. Even if I interpret word for word what the provider asked, an old lady wouldn't understand the questions. How would she understand what he asked her? [HI #10]

Although the preceding examples did not involve encounters with GCs, the GCs in our study reflected some of the attitudes and distrust that the interpreters described. GCs emphasized their expectation of literal, neutral, and faithful relay of information by the interpreter (the conduit model). When a GC perceived that the information being provided to the patient and the responses they received back did not match, they questioned the interpreter's competence and ability to provide a transparent and accurate interpretation. When the GC could not speak or understand the patient's language, they felt vulnerable with respect to the level of control they could have over the session.

Genetic Counselor: There'll be long exchanges that are just not what, you know, I said or like - I can tell that in Spanish and I can sort of like manage that. But, I have no idea what's going on in Vietnamese... So, I just I feel like, purely based on how long someone's talking versus what is said, ... that can't be an accurate representation of what either I communicated or what the patient said... [I]f it's really bad you can just say, you know, like, "Tell me what she's saying" or like, "There must have been more to it than that." But most of the times... it'll cause me to ask more direct questions so that like I feel like oh, then I can actually ascertain exactly what's happening here. [GC #3]

Only one GC acknowledged that in such cases interpreters might not be at fault, given that in her experience patients do not always respond to the counselor's questions in a concise manner. Such findings demonstrate the critical role that trust plays in the interpreter-provider dynamic, highlighting the need for open communication between GCs and interpreters.

Discussion

Parameters of the interpreter role

Healthcare interpreters have been conceptualized as conduits, with a neutral role in the medical encounter and an invisible presence limited to facilitating verbatim provider-patient communication. According to Dysart-Gale, the interpreters' code of ethics directs them to "transmit the message in a thorough and faithful manner," and to interpret "everything that is said by all people in the interaction, without omitting, adding, condensing or changing anything" (Dysart-Gale, 2005, p. 93). However, interpreters in our study indicated that following the conduit model is often impractical due to patients' limited health literacy and/or cultural beliefs. Instead, most interpreters perceived their role to include acting as an advocate and cultural broker for patients navigating an often unfamiliar and intimidating healthcare system. Indeed, some interpreters explicitly stated that empowering patients to obtain fair and equal healthcare services was a motivation for entering the profession.

Some interpreters stated that strict interpretation under the conduit model could limit their ability to account for subtle cultural differences between patient and provider. Others were aware of the influence that culture can have on patients' understanding of the abstract concepts that are frequently part of the genetic counseling encounter. This was particularly evident for one of the interpreters in our study who served Latino patients. In his opinion, for some Latino patients who hold deep religious beliefs, the arbitrary nature of genetics and the hereditary susceptibility to cancer could be a difficult concept to accept. Although not all Latino patients that this interpreter has served or may serve in the future are religious, it is important to acknowledge that his familiarity with Hispanic cultures allows him to be sensitive to those who are. Thus, he is a resource for patients as well as for GCs, particularly those who may be less familiar with Hispanic cultures.

In observed CGC sessions that were part of the larger investigation of which our study is one part, Kamara and colleagues found that for low-income LEP Latina women undergoing CGC, adoption of such nontraditional roles by interpreters promoted better communication between patients and GCs and potential errors in interpretation were avoided (Kamara et al., 2018). They cite one instance of cultural brokering in which the interpreter was able to clarify for the patient that the documents the GC requested only involved documentation of income to facilitate subsidized testing and not, as the patient feared, immigration documents (Kamara et al., 2018). More broadly, our findings are consistent with other research that has found that the conduit model, in failing to account for socioeconomic and cultural factors that influence communication dynamics, resulted in suboptimal interpretation that impacted communication (Butow et al., 2011; Dysart-Gale, 2007; Hsieh, 2008). Beltran Avery (2001) proposed expanding the interpreter role to include three additional functions: clarifier, in which the interpreter departs from the conduit model when the information or terms used by the provider have no linguistic equivalent in the patient's native language; patient advocate, in which the interpreter acts on behalf of the patient

after the medical session; and cultural broker, in which the interpreter provides a necessary cultural framework for understanding the message being interpreted. This model provides a useful framework within which our findings could be more explicitly formulated and validated.

Some interpreters in this study conveyed an authoritative understanding of patients' culture because it was theirs as well. Such cultural knowledge must be used judiciously; generalization from one's own experience and perspective is problematic, especially for cultural groups as large and diverse as Latino or Chinese. It is also important that interpreters recognize that the providers for whom they are interpreting may have experience with and be sensitive to patients' beliefs and culture. Some providers, such as GCs include cultural sensitivity among the tenets that govern their work ethic. Nevertheless, an expanded interpreter did not appear to have been accepted by providers in our study, in part due to their distrust of the interpreters.

Trust in the relationship between interpreters and genetic counselors

Trust among members of the healthcare team is essential to providing quality care (McDonald, Jayasuriya, & Harris, 2012; Pullon, 2008). Our data, with the complementary viewpoints of GCs and medical interpreters, provide an opportunity to analyze the areas of mistrust we identified and propose potential ways to address them. Mistrust between GCs and interpreters is due, in part, to the differing practices and goals of the two professions. GCs strive to convey complex, nuanced information in a precise and carefully constructed way while also addressing psychosocial aspects of genetic testing and hereditary conditions. Interpreters bridge the linguistic, educational and cultural differences inherent in conveying this information to the patient as well as in transmitting patient responses and needs to the GC.

Hsieh and colleagues found that trust, as a pillar of the provider-interpreter relationship, rested on providers' assessment of interpreters' competence as measured by their linguistic ability (e.g., finding equivalent medical terms) rather than cultural competence (Hsieh, Ju, & Kong, 2010). Similarly, GCs in our study equated interpreters' competence with their ability to translate verbatim, rather than by their ability to interpret providers' and patients' utterances to facilitate effective patient-provider communication. However, limiting the assessment of competence to verbatim translation overlooks the complexities that interpreters face, including the limitations of the conduit model. Interpretation problems may be due to technical difficulties (discussed in the next section), the interpreter's limited knowledge of genetic concepts and terminology, lack of relevant terms in the patient's language, or the perceived need to address cultural or psychosocial issues. Conversely, interpreters may misunderstand or underestimate the challenges that GCs face as they attempt to convey complex information and provide psychosocial interventions, each of which also require careful assessment. Both interpreters and GCs need to be aware of the other's aims and methods in order to promote trust.

For GCs, interpreters' limited knowledge contributed to their distrust of interpreters because they were able to surmise that some interpreters did not sufficiently understand genetic counseling content to translate it effectively (Joseph et al., 2017). In some cases, that distrust was warranted. Interpreters' survey responses indicated that most had no training in genetics, and that training on basic genetic concepts would enhance their ability to interpret effectively for genetic counseling. Similarly, a recent study on the perspectives of HIs serving Hmong patients in a genetics setting also identified the need for training in genetics and genetic concepts as a way to mitigate the difficulties associated with interpreting (Krieger et al., 2018).

Based upon findings of the present and related studies in which we observed uneven interpretation quality during genetic counseling (Cheng et al., 2018; Joseph et al., 2017; Kamara et al., 2018), we developed a training workshop to provide interpreters with an overview of the key concepts in genetics in general, and cancer genetics and genetic counseling specifically; it includes bilingual glossaries, vocabulary exercises and role plays (Roat et al., 2015). Furthermore, to improve interpreter and patient comprehension, we developed a training curriculum to teach GCs how they can use plain language (Stableford & Mettger, 2007), reduce the overall quantity of information they provide, and give interpreters explicit permission to ask for clarification (Joseph, Pasick, Schillinger, Guerra, & Rubin, 2018).

Both parties also must recognize that the medical encounter occurs in the context of a hierarchical relationship, in which the GC (or other healthcare provider) has the power, and hence the responsibility to set the tone so trust can be created in the interaction with an interpreter. Creating an environment that welcomes open communication – for example, in which the interpreter feels comfortable raising issues such as the need to address a cultural expectation as part of the interpretation process – may mitigate the negative effects of the structural power dynamic and facilitate a trusting relationship between counselors and interpreters.

Conflicting views concerning a provider's limited knowledge of the patient's language is another facet of the larger issue of trust. Most interpreters were native speakers who expressed confidence attaining grammatically and linguistically faithful translations of the providers' statements. Particularly, Spanish-speaking interpreters considered themselves experts in the patient's native language and took offense when GCs or other providers who had limited Spanish proficiency corrected them while interpreting. GCs who understood some Spanish sometimes thought that important content was lost. Although they were not always sure if a perceived mistranslation was actually a “nuanced” way to accurately communicate the information to the patient, they sometimes felt compelled to “correct” the interpreter. Thus, for the GCs, limited knowledge of Spanish was an asset when there was no interpreter (e.g., when an LEP patient declined an interpreter), but could be problematic when an interpreter was present, particularly if the GC did not acknowledge her limitations and defer to the interpreter's language expertise. Although this is largely an individual issue for GCs – when and how should they intervene – it is a systemic issue for interpreters of Spanish in that, despite their language expertise and interpreter skills, they were commonly second-guessed by GCs.

Interpreter working conditions

Issues associated with remote interpretation—poor equipment, background noise in the call center and exam rooms, and a high volume of cases with limited time for review, rest or preparation between cases—contributed to high levels of stress. Improvements in interpreters' working conditions (e.g., providing interpreters with high-quality noise-canceling headsets, and/or a floor plan that minimizes background noise; establishing a reasonable break between calls to allow interpreters to reorganize their thoughts, especially after emotionally taxing interpretations) have the potential to improve the services they provide and job satisfaction. Consistent with our findings, previous research has demonstrated that HIs in a number of settings prefer in-person over telephone interpretation (Locatis et al., 2010; Saint-Louis, Friedman, Chiasson, Quessa, & Novaes, 2003) and that telephonic interpretation is often inadequate for clinical interactions with substantial educational/psychosocial components (Price, Perez-Stable, Nickleach, Lopez, & Karliner, 2012). Most GCs in this study agreed with interpreters that in-person interpretation is preferable to remote services given the substantial educational and emotional components of CGC. However, due to the costs and labor associated with in-person interpretation, and the demand for interpreters, it is likely that the trend in remote interpretation will continue to grow. In combination with the accelerated translation of genetics and genomics into many fields of clinical care, it is critical to find ways for genetics professionals and interpreters to work effectively together for LEP patients.

Limitations

Although the small sample was appropriate for our exploratory study, data saturation was not reached (Saunders et al., 2018), and the generalizability of our findings is limited. GCs were recruited from two public hospitals; interpreters from one, and all participants were from one geographic region. GCs' stylistic approaches to counseling are highly individualized, and the interpreters' educational levels, training and experience varied broadly. As such, the GCs' experiences with and perspectives on interpretation services and the interpreters' views, including suggested improvements to working conditions, might not reflect those of the larger population of GCs and interpreters. Nevertheless, the study has identified important issues that are consistent with previous reports and thus have potentially wider relevance, including for interpretation services in other public hospital and low resource settings.

Directions for future research

The findings of this exploratory study would be strengthened by expanding this research to larger populations of GCs and HIs. Broadening the spectrum of languages and genetic counseling subspecialties will further our understanding of the many factors impacting the effectiveness of interpreter-mediated genetic counseling encounters. Additionally, the applicability and effectiveness of specific strategies for GC and interpreters to improve their working relationship and outcomes for LEP patients should be assessed systematically.

HIs considered CGC to be challenging due to its complexity, and the majority of interpreters and GCs expressed that in-person interpretation is preferred for these encounters. Further investigation is needed to determine whether this perspective holds for each type of CGC encounter (initial intake, pretest, results disclosure, and posttest sessions). Such an investigation would provide valuable information to determine when GCs should request in-person interpreters and under what circumstances phone interpretation is acceptable. Further research on phone interpretation of GC encounters also is needed, given the increased use of telephone interpreters in healthcare.

Conclusions

The process of interpretation in the CGC setting involves many challenges for both HIs and GCs that, if not addressed, may result in poor healthcare experiences and outcomes for LEP patients. We identified several practices that could promote an effective working relationship between interpreters and GCs. The data also provide insight into the structural working conditions for interpreters in a busy public hospital, and illustrate how CGC sessions differ from many appointments, including the longer length, the psychosocial/emotional complexity, and the required command of technical concepts not necessarily required in other medical encounters. To ensure that health disparities do not widen with the expansion of genomics in medicine and the increasing availability of genetic services to LEP and other underserved patients, a better understanding of the role healthcare interpreters play in facilitating communication is needed, and improved strategies to support their effectiveness should be supported by further research.

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