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Erica Liebermann

University of Rhode Island, eliebermann@uri.edu

Peter Taber

Alexis S. Vega

Brianne M. Daly

Melody S. Goodman

See next page for additional authors

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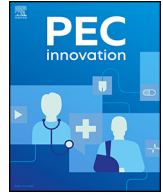
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Authors

Erica Liebermann, Peter Taber, Alexis S. Vega, Brianne M. Daly, Melody S. Goodman, Richard Bradshaw, Priscilla A. Chan, Daniel Chavez-Yenter, Rachel Hess, Cecilia Kessler, Wendy Kohlmann, Sara Low, Rachel Monahan, Kensaku Kawamoto, Guilherme Del Fiol, Sandra S. Buys, Meenakshi Sigireddi, Ophira Ginsburg, and Kimberly A. Kaphingst



Barriers to family history collection among Spanish-speaking primary care patients: a BRIDGE qualitative study

Erica Liebermann^{a,*}, Peter Taber^b, Alexis S. Vega^c, Brianne M. Daly^d, Melody S. Goodman^e, Richard Bradshaw^b, Priscilla A. Chan^f, Daniel Chavez-Yenter^{c,d}, Rachel Hess^g, Cecilia Kessler^d, Wendy Kohlmann^d, Sara Low^d, Rachel Monahan^f, Kensaku Kawamoto^b, Guilherme Del Fiol^b, Sandra S. Buys^{d,h}, Meenakshi Sigireddi^f, Ophira Ginsburgⁱ, Kimberly A. Kaphingst^{c,d}

^a College of Nursing, University of Rhode Island, RINEC, 350 Eddy Street, Providence, RI 02903, USA

^b Department of Biomedical Informatics, University of Utah, 421 Wakara Way, Suite 140, Salt Lake City, UT 84108, USA

^c Department of Communication, University of Utah, 255 S. Central Campus Drive, Salt Lake City, UT 84112, USA

^d Huntsman Cancer Institute, 2000 Circle of Hope Drive, Salt Lake City, UT 84112, USA

^e School of Global Public Health, New York University, 726 Broadway, New York, NY 10012, USA

^f Perlmutter Cancer Center, NYU Langone Health, 160 E. 34th Street, New York, NY 10016, USA

^g Department of Population Health Sciences, University of Utah, 295 Chipeta Way, Salt Lake City, UT, 84108, USA

^h Department of Internal Medicine, University of Utah, 30 N 1900 E, Salt Lake City, UT 84132, USA

ⁱ Center for Global Health, National Cancer Institute, 9609 Medical Center Drive, Rockville, MD 20892-9760, USA

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ABSTRACT

Objectives: Family history is an important tool for assessing disease risk, and tailoring recommendations for screening and genetic services referral. This study explored barriers to family history collection with Spanish-speaking patients. **Methods:** This qualitative study was conducted in two US healthcare systems. We conducted semi-structured interviews with medical assistants, physicians, and interpreters with experience collecting family history for Spanish-speaking patients.

Results: The most common patient-level barrier was the perception that some Spanish-speaking patients had limited knowledge of family history. Interpersonal communication barriers related to dialectical differences and decisions about using formal interpreters vs. Spanish-speaking staff. Organizational barriers included time pressures related to using interpreters, and ad hoc workflow adaptations for Spanish-speaking patients that might leave gaps in family history collection.

Conclusions: This study identified multi-level barriers to family history collection with Spanish-speaking patients in primary care. Findings suggest that a key priority to enhance communication would be to standardize processes for working with interpreters.

Innovation: To improve communication with and care provided to Spanish-speaking patients, there is a need to increase healthcare provider awareness about implicit bias, to address ad hoc workflow adjustments within practice settings, to evaluate the need for professional interpreter services, and to improve digital tools to facilitate family history collection.

1. Introduction

Family history is recognized as an important tool in primary care for assessing the risk of common diseases [1-3]; focusing health promotion counseling; tailoring recommendations regarding screening and surveillance; and offering referral for genetic services, where appropriate [4-6]. Known challenges to family history collection in primary care include time constraints and competing demands in the clinical setting, as well as

limited training and prioritization of family history collection among staff and providers [1,7,8]. Patient self-report of family history is also limited by incomplete knowledge of their family history, particularly regarding extended family members' health history [9,10]. An accurate and complete family history is important in identifying individuals who may be at increased risk for cancers and meet eligibility criteria for cancer genetic services [4,11]. Appropriate and timely referral for genetic services depends on both obtaining and responding to self-reported family history.

* Corresponding author.

E-mail address: eliebermann@uri.edu (E. Liebermann).

Clinical decision support (CDS) tools are being evaluated as a strategy to facilitate evidence-based practice in primary care for referral of unaffected individuals who meet family history criteria for cancer genetic services. [12-14]. The utility of these CDS tools depends on the availability and comprehensiveness of family history data in the electronic health record (EHR). Baseline EHR data for the Broadening the Reach, Impact, and Delivery of Genetic Services (BRIDGE) study, a genetic services outreach intervention study in two large health systems in Utah and New York (protocol described in detail elsewhere [12]), revealed significant differences in availability and comprehensiveness of family history data for Hispanic and Spanish-speaking patients as compared to non-Hispanic and English-speaking patients [15]. “Hispanic” is the terminology used for ethnicity category in these EHR systems; we use this terminology throughout the manuscript for consistency.

Prior research has shown that Spanish-speaking and Hispanic individuals in the US face barriers in access to and utilization of primary care services, including language barriers, inadequate insurance coverage, and lack of a consistent primary care provider [16-18]. There is limited information regarding racial/ethnic differences in family history reporting within the primary care encounter. One study found that Black, Hispanic and Asian patients were significantly less likely to report a family history of cancer than non-Hispanic White patients [19] and another study found that White women were more likely than non-White women to be asked about a family history of breast cancer [20]. Another national study found that immigrants to the US (foreign-born vs US-born) were about one third as likely as non-immigrants to report a family history of cancer, even after accounting for sociodemographic factors and cancer-related knowledge [21].

Gaps in family history for patients who self-identified as Spanish-speaking and/or Hispanic could exacerbate disparities in multiple preventive health interventions in addition to referral for cancer genetics services [22-24]. The purpose of this qualitative study was to explore factors that might affect the collection of family history, and cancer family history, in particular, for Spanish-speaking and Hispanic patients in primary care settings in two large healthcare systems with different structures and patient populations.

2. Methods

2.1. Participants and Setting

The study was conducted in the primary care setting in major healthcare systems in Utah and New York. The Utah health system serves a vast geographic area encompassing both rural and urban settings. In New York, the health system is made up of a large number of ambulatory health centers and affiliated hospitals serving a diverse population in the New York metropolitan area. The study recruited providers, support staff, and interpreters employed or contracted by the respective healthcare systems with experience providing services for Spanish-speaking patients. Purposive sampling was used to select clinics in Utah that serve many Spanish-speaking patients and ambulatory centers in varied locations across the metropolitan area in New York. We estimated a sample size of 5 interpreters and 8-10 MA/providers for each health system, and interviews continued until data saturation was achieved [25]. Both health systems currently use the same EHR system with a standardized module for family history collection. There were differences between the two systems in terms of workflow and configuration; accordingly, different types of health center staff were interviewed. Health system partners in Utah reported medical assistants (MAs) typically enter the family history and the primary care provider reviews it [26], whereas in New York family history was reportedly primarily collected by providers. The study recruited six physicians (all from New York), 11 medical assistants (nine from Utah and two from New York), and 11 interpreters (six from Utah and five from New York). Limited demographic data were collected from participants in order to protect their confidentiality.

2.2. Instruments

A semi-structured interview guide (Supplementary Appendix A) was designed to understand: the current workflow for collecting and recording family history for Spanish-speaking and Hispanic patients; the type of family history collected; the barriers and facilitators to collecting family history information from these patients; and suggestions for changes to the workflow. Examples of the types of open-ended questions and probes used were: “What type of information about family history of cancer is collected?” and “How much detail is collected about cancer family history, such as type of relative, type of cancer, and age at diagnosis?”. The instrument was piloted with three MAs in the participating Utah healthcare system via research assistants trained by a researcher with extensive qualitative research experience (KAK). A modified interview guide was created for interpreters (Supplementary Appendix B).

2.3. Procedures

In both locations, we initially contacted office managers of the selected health centers. The office managers then sent materials about the study to interpreters and providers/MAs and coordinated scheduling with the interviewer. Interviews (n = 28) were conducted by trained research assistants in Utah from March-April 2021 and by an experienced qualitative researcher (EL) in New York from May-August 2021. Semi-structured interviews were administered in person in Utah (n = 15) and via video in New York (n = 13) due to COVID-19-related restrictions on non-clinical visits to the health center. The average interview time was 19 minutes, with minimum and maximum times of 11 and 30 minutes, respectively. Interviews were digitally recorded and professionally transcribed. We did not review transcripts directly with participants but preliminary findings were discussed with clinical leaders in Utah.

2.4. Reflexivity/positionality

Team members represented a range of personal experience and professional disciplines [25]. One team member is a White non-Latinx healthcare provider with extensive clinical and research experience working with Spanish-speaking/Latinx populations. One team member is a White non-Latinx anthropologist with ethnographic field experience working with diverse Spanish-speaking populations in Central and South America. One team member is a Latinx graduate student with interests in health disparities and health communication. One team member is a White non-Latinx health communication researcher who has conducted community-engaged research with Latinx communities. All members of the team speak Spanish. The team sought to use its experiences working with diverse Spanish-speaking populations to remain sensitive to the heterogeneity of the target population, and to remain mindful of the complicated power dynamics that may exist between providers, MAs, and Spanish-speaking patients when interpreting informants' comments.

2.5. Analysis

Transcripts were added to a database in the qualitative software Dedoose (Dedoose, Los Angeles) and iteratively reviewed by four team members (EL, PT, AV, KAK) to gain familiarity with the content. Codes were iteratively designed based on emergent findings in the corpus and extensive discussion and consensus-building about the meaning and scope of codes. A coding structure was created with 13 overarching codes and 45 subcodes. Interrater reliability was assessed via independent coding by three coders (EL, PT, AV) for a subset of the transcripts (n = 5) using Fleiss' kappa (the relevant kappa measure for assessing agreement between more than two independent raters) in Stata v15 (StataCorp, College Station, Texas). Coding achieved a final kappa score of .68 (“substantial” agreement) for all three coders. Coding for remaining transcripts was done individually, with any questions brought to the team to achieve consensus. Thematic analysis was used to structure the codes and identify

Table 1
Exemplar quotations for patient knowledge barriers.

No.	Quotation
1	When people, especially for the Hispanic people, they are coming here to United States and they're going to be—if they have been living here and they have disconnected from their families in their countries, and then that is hard sometimes to find out about what is going on because they are disconnected. To find that information from relatives is sometimes it's not easy. I think that is one of the issues. Yeah. To collect information from family when they are farther away from them. (Interpreter, Utah)
2	I think it would just be a language and knowledge barrier. They may not know. They may have had an—let's say they've been living in the United States. They have a family member that has been in the Dominican Republic...or Puerto Rico where they just don't know. (Provider, New York)
3	I think that culture will be also a factor there that we don't like to pass on information that is perhaps negative, and that it is better just to keep quiet or something like that. It may be that's one of the reasons, I'm not sure. I will say that definitely we always try to protect people from bad news and things that will cause them harm...We just don't share it. That might be why a lot of people say, "I don't know," because they're never told (Interpreter, Utah)
4	In Latino culture, there are illnesses that are kind of taboo. You don't discuss it with everybody. Not every family member knows. Like cancer...(Interpreter, New York)
5	I think it's largely a comfort level with the medical system as well as what families discuss, but there is also an educational level and component to understanding history and what was discussed, and so, I would say overall, there probably is more of that issue in the Spanish speaking population generally, but I've seen even in that Spanish speaking population quite a range in terms of what patients know...there's anything from a very high level of knowledge and sophistication of understanding medical conditions to those who really it's just not something that's discussed in the family at all and everything in between. (Provider, New York)
6	Especially our Hispanic populations. They don't understand. Not only Hispanic...Asians, Jamaican people, they don't understand if you talk to them [in] medical terminology. You have to tell them like diabetes, hypertension, what is that. Oh, when your blood pressure is out of range. Cancers, if someone, your dad or your grandpa or your uncle were diagnosed with prostate, and we show them where the prostate is. (MA, Utah)
7	I think the biggest things with a lotta [sic] immigrants, just medical sophistication to describe what it is. They tend to know diabetes pretty well. With cancer, it's very vague histories, usually, 'cause most people don't have the sophistication to distinguish one cancer from another. If someone's very educated, then they often speak English, and we usually don't have as much of a difficulty. Although, still, sometimes they're not sure. (Provider, New York)

themes most relevant to the research questions [27]. Differences in themes were initially explored across organizational roles (MAs, providers, interpreters), but with the exception of one theme that related specifically to interpreter observations and experiences no differences were found across these categories; themes are therefore presented as overall themes rather than by categories. Exemplar quotes for the themes are presented in the tables below.

3. Results

Qualitative interviews with healthcare providers, MAs and interpreters elucidated themes related to workflow details and adaptations for Spanish-speaking patients as well as barriers to family history collection. Some of the barriers noted by interpreters were based on their observations of the provider/MA and patient interaction and some related to communication between interpreters and patients or triadic communication between providers, interpreters, and patients. Barriers to family history collection were identified at the individual patient level, at the interpersonal communication level, and at the organizational level.

3.1. Individual-level barriers

The most common patient-level barrier to family history collection with Spanish-speaking patients identified by MAs, providers and interpreters was the perception that some Hispanic patients had limited knowledge of family health history for a variety of reasons including physical distance from family of origin (Table 1, Quotation No. 1 and 2) and cultural taboos

around cancer limiting information shared within families (Table 1, Quotation No. 3 and 4). A second barrier was the perception that Hispanic patients had limited health literacy in general (Table 1, Quotation No. 5 and 6). One provider expressed assumptions about immigrant patients' cancer health literacy related to perceived educational levels and language abilities (Table 1, Quotation No. 7).

3.2. Interpersonal communication barriers

Several challenges were identified related to triadic communication between providers or MAs and Spanish-speaking patients communicating via an interpreter, as well as dyadic communication between interpreters and patients themselves. The first interpersonal communication barrier identified was that Spanish language abilities vary among providers. For example, health center providers and MAs might speak Spanish and think they do not need to use an interpreter, however their Spanish fluency may not be sufficient to collect a detailed family history (Table 2, Quotation No. 1). Interpreters noted that variations in dialect and country-specific Spanish language used for medical terminology can cause challenges in communicating with patients regarding health/family history (Table 2, Quotation No. 2). Interpreters described the process of adapting their language and asking clarifying questions to ensure patient understanding (Table 2, Quotation No. 3).

The second barrier was that differences in provider/MA styles of eliciting family history of cancer led to more or less complete family histories; this barrier was generally based on interpreter observation. For example, some providers/MAs asked non-specific questions (e.g., "any

Table 2
Exemplar quotations for complexities of triadic interpersonal communication with Spanish-speaking patients.

No.	Quotation
1	Sometimes, MAs or even doctors...speak some [Spanish]. They try to do the interview without an interpreter...some doctors they say, "Oh no. I speak Spanish, so I don't need an interpreter." They will skip a lot of stuff just to go to the point because that is what they are trained to do. That may affect also gathering information from them a little more in depth than the basic...if an interpreter is not used, then perhaps that will be part of one of those things that will be lost because people don't want to go into much details. (Interpreter, Utah)
2	Just talking to people because people use a lot of jargon from Mexico, from Peru. You have to learn how to say things, so they understand that instead of the way that I learned it when I was a kid. I'm from Panama so not many people speak—or there are some words that we use that no one else uses. (Interpreter, Utah)
3	My role is basically to bridge the gap in communication, so between provider and patient and/or family. I basically take what the provider will say, let's say in English, and convert it into the Spanish language as close as possible to the culture that I am presented with, so depending on where the patient may be from, whether they may be New Yorkers or not or they're from—they're recent arrivals. It depends on that, but I do it as closely as possible to theirs without compromising the actual information that's being presented by the provider (Interpreter, New York)
4	Generally the most, that I can think of, it's usually a pretty generic question of "Is there any significant family medical history that we need to be aware of?" Something very along that lines. They may give examples of like diabetes, heart disease, or something of that nature, but it's usually not specific to like, "Did your mother have anything? Did your father have anything? Does your grandparent, your uncle, your brothers, sisters?" (Interpreter, Utah)

Table 3
Exemplar Quotations for Interpreter interpersonal communication role in facilitating visit.

No.	Quotation
1	If needed, we would clarify if there's something that either we, as the interpreter, didn't understand or didn't hear, or if we see that maybe the patient isn't understanding or if the provider, maybe if it's something culturally bound that the provider doesn't understand, we may need to intervene and kind of clarify, you know, mitigate the understanding there. (Interpreter, Utah)
2	I think that the [family history] question can be asked—it's a very direct question that it should be easy to do, but they can ask the question, and then try to find more about it after they ask the question. It's not to replace the question with something else, but just maybe show more interest, empathy on the patient and the family history and all that. Like you care, you know? It's not only statistics. I care about you. I care about what you have gone through, your family have gone through. (Interpreter, Utah)
3	We have to be very flexible [as] an interpreter. You are more than an interpreter when you step in a clinic setting. Sometimes you are the patient navigator. You have to know a little bit about insurance, a little bit about the specialty that you're talking about. Yeah, most of the times you just help them with the form. Sometimes you even have to go back and forth with the provider. Sometimes you even have to call other people just to fill the form because you have missing information. As an interpreter, it's more than interpreting. Sometimes [you] navigate the system with them. (Interpreter, New York)
4	I do feel like there is some discrepancies on the iPad versus face-to-face. I don't know that a lot of our population is comfortable using an iPad. I feel like they're more personal when the interpreter is face-to-face versus on the iPad. My verbiage is the same, but I think that it comes across a little differently on the iPad versus in-person. I think if it's on the iPad, it's just like—I don't know. You don't get that connection, that personal connection with the interpreter... I think that a lot of information might be missed when the patient is talking to an iPad. (MA, Utah)
5	Sometimes they're both my patients. Sometimes one is coming to support and hear the details of my recommendations, which I think is always good practice, but in terms of... Spanish speaking patients, we have the official interpreter, either the video or the audio depending upon availability, and if there's another family member that may be helpful as well. (provider, New York)

updates in family history?" or "any family history of cancer?") compared to others that asked detailed questions about first and second-degree relatives, as well as questions about the types of health problems they had and/or detailed questions about specific cancer types (Table 2, Quotation No. 4).

Professional interpreters (vs. Spanish-speaking health center providers or staff) shared some insights about their experiences and observations in interpreting for Spanish-speaking patients that span the categories of interpersonal communication barriers and organizational-level barriers. With respect to interpersonal communication, though professional interpreters often stated their assigned role as "just interpreting" what the patient or provider/MA says, their accounts illustrated a broader role in facilitating visits for Spanish-speaking patients. They described a role as cultural brokers, intervening when they perceived linguistic and/or cultural gaps in patient-provider understanding (Table 3, Quotation No. 1), and suggested that more empathetic styles of provider communication would yield more information from Spanish-speaking patients (Table 3, Quotation No. 2). One interpreter described a role as patient navigator for the visit (Table 3, Quotation No. 3).

From the perspective of health center staff, in working with interpreters, medical assistants, particularly in Utah, had a strong preference for in-person interpreters as compared with remote interpreters. Remote interpreters are accessed via video chat on a standing tablet that is brought into the room. Health center staff saw the lack of personal connection with a virtual interpreter as a barrier to effective communication and perceived a difference in quality of interpretation (Table 3, Quotation No. 4).

A few providers in New York commented that it can be useful to have family members present during the visit, in addition to the formal interpreter, to add family history information and/or partially interpret for the visit (Table 3, Quotation No. 5).

3.3. Organizational barriers

A common organizational barrier identified was that time pressures may reduce family history-taking effort in a clinic setting. Based on this premise we examined what factors might add time pressure in encounters with Spanish-speaking patients specifically, and thereby limit family history collection. Providers and MAs noted that locating and working with interpreters adds extra time to the visit, particularly if the need for an interpreter is not documented in the EHR (Table 4, Quotation No. 1 and 2), and that the health intake takes longer when using an interpreter (Table 4, No. 3 and 4). Interpreters or other staff observed that MAs may abbreviate the health intake with Spanish-speaking patients, because of the extra time required (Table 4, Quotation No. 5 and 6).

Providers and MAs described ad hoc adaptations to workflow with Spanish-speaking patients that could present a barrier to complete family history collection. For example, in settings where MAs would customarily collect family history, they may defer this to providers who speak Spanish, leaving a potential uncertainty of when and whether a complete family history is collected or updated (Table 5, Quotation No. 1). Workflow was described as variable based on what combination of Spanish-speaking providers and/or MAs are available (Table 5, Quotation No. 2). In situations

Table 4
Exemplar quotations for time pressures with Spanish-speaking patients.

No.	Quotation
1	[with] any kind of interpreter...even if you have the iPad or if you have the translator here in person, sometimes it takes a long time. (MA, Utah)
2	Typically by the time you get an interpreter up there and ready, you don't do all the extra stuff. Those questionnaires that you would normally do, you don't usually do because it's taken so much time to get the interpreter up there. (MA, Utah)
3	It's the same process. It's the same process through each field. It may take a little bit longer because I have to ask other questions or hand them the question, and then the interpreter has to repeat, and then she will answer the interpreter, and then the interpreter sends that information back to me. It just takes a little longer, but it's the same process. (MA, New York)
4	If the patient does not speak English, this is much more difficult. If there's a translator—'cause the translation takes a significant amount of time, so the visit takes longer, especially if they have acute issues that they brought with them besides being physically examined, and so I would say that the family history, outside of me asking for specific cancer, is—I would say it's much more shallow. I would say that their knowledge of family history is also less. They usually have to go home and ask and then come back and tell me. They just may not know. (Provider, New York)
5	Another thing is sometimes, even if it's an adult and they do grab an iPad, sometimes they just rush it just because it takes longer to do the intake and MAs are trying to keep on top of a schedule. We're trying to not fall behind. We're like the provider's gonna review everything with them anyway, hopefully they do, though obviously we're not in the room. Yeah, if they're Spanish speaking, yeah. I think if the medical system is not Spanish speaking, they will have to grab the iPad, and I feel like it's usually a more rushed intake from what I've seen. (MA, Utah)
6	I would say [the challenge is] mostly timing because you don't have much time to go back and forth with the patients. Sometimes the provider will tell you, "Just let me see the patient first." Sometimes they would say, "We don't even take a look at that. I just wanna see the patient for time's sake."...it's very often that you find that you don't have time to help the patient with the forms [before the provider comes in]. (interpreter, New York)

Table 5
Quotations for Ad hoc workflow adaptations with Spanish-speaking patients.

No.	Quotation
1	As far as the Spanish-speaking patients, when I room the patients, with my limited Spanish—the doctor is the one that actually, typically, will go over that information. We do have another Spanish-speaking MA that works for the provider, and both of their Spanish is amazing. She will collect the information, and she's great about going through all of the history, hitting everything. As far as when I'm in there, it's very—it's more limited. I might get the smoking history and the alcohol history and all of that. When it comes to family history, it's something that the provider does go over with the patient. (MA, Utah)
2	What happens, at least in this practice, is that because I speak Spanish, when there's a Spanish-speaking patient that only speaks Spanish, and we have a couple of MAs that do speak Spanish, but if none of them are available, that part will be left blank for me to do it...but I don't know what happens with other providers. That would be an interesting question to ask other providers that also see Latinos. (Provider, New York)
3	There's some doctors [that speak Spanish] but neither of their medical assistants speak Spanish. It causes us to use an interpreter for only our check-in process to have our doctor go in and be able to talk to them. We don't need the interpreter anymore. The checkout process, we usually need the interpreter again and they're not willing to come back up. (MA, Utah)

where part but not all of the health center team (providers, MAs, receptionists) speak Spanish, interpreters may be utilized for only part of the visit and there may be a disruption in facilitating patient communication throughout the entire visit (Table 5, Quotation No. 3).

4. Discussion and conclusion

4.1. Discussion

In this study, we explored factors that affect the collection of general family history as well as cancer family history information with Spanish-speaking patients in two large health systems in Utah and New York, from the perspective of healthcare providers, staff and interpreters. We identified multi-level barriers to family history collection with Spanish-speaking patients in the primary care setting.

At the individual patient level, providers, staff and interpreters perceived that some Spanish-speaking patients' limited knowledge of family history was a barrier to accurate and complete family history collection. This is consistent with prior research findings regarding patient knowledge level as a barrier to family history collection [9,21]. A previous qualitative study similarly found that the level of patient family history knowledge limited cancer family history collection and that language was often seen as a barrier to accurate family history collection even if interpreter services were used [28]. Some comments from providers and staff in this study suggest implicit bias and a tendency towards population-level generalizations and assumptions about Spanish-speaking patients' health literacy and knowledge of family history that may reduce family history elicitation effort and impede overall communication regarding family history. Prior research regarding providers' cultural humility in working with Hispanic and Spanish-speaking patients [29] and more recent research on implicit bias among healthcare providers [30,31] suggest that provider perceptions may not accurately reflect the health knowledge and experiences of their Spanish-speaking patients.

At the interpersonal communication level, the lack of structured processes for interpersonal communication of family history, despite having structured family history EHR fields, presents a barrier to consistent family history collection. This finding adds to the limited existing literature showing that approaches to family history communication vary widely by type of clinical visit (i.e., routine vs. problem-focused) and whether it is a new or established patient encounter [26], and highlights the need for standardization of family history collection processes even within visit types such as wellness visits. Our findings also suggest that the quality of triadic communication between providers/staff, interpreters and patients affects the quality of family history information obtained, and that formal interpreters are important facilitators to patient-provider/MA communication, beyond the simple transmission of linguistic messages. The more expanded role as cultural brokers described by interpreters in our study, and sometimes as mediators and patient advocates, is highlighted in previous studies [32,33], but has not been investigated in the context of family history collection. More generally, with regard to quality of care (including patient satisfaction, utilization and clinical outcomes), prior research has shown that the use of professional interpreters vs. ad hoc interpreters improved

understanding and overall clinical care for patients with limited English proficiency [34,35] and that interpretation by health center staff who are not formally trained interpreters may result in errors and miscommunication between patients and providers [36]. Though a systematic review found no differences in patient satisfaction with in-person or remote professional interpreters [37], such nuanced interpreter roles as described above raise the question of the extent to which remote interpreters can meet the full needs of interpersonal communication in a healthcare encounter.

At the organizational level, time pressures frame many of the challenges described in working with Spanish-speaking patients in primary care. Time is commonly discussed as a main barrier to guidelines-based practice in healthcare including thorough family history collection [8,38,39], but these time pressures have mainly been examined in the context of care of English-speaking patients, without the use of interpreters.

There was little discussion in the interviews regarding the use of the online patient portal for pre-visit entry of patient and family history information, which can reduce time needed for data entry at the time of the visit. The patient portal was not available in Spanish in Utah at the time these data were collected, but even in New York where Spanish functionality is enabled providers and MAs thought this was not widely utilized by their Spanish-speaking patients. Prior research suggests that patient portals, often designed with limited patient input, do not match patients' needs and expectations in terms of information and functionality and therefore have lower than expected uptake [40,41]. Underutilization of the patient portal may limit Spanish-speaking patients' ability to indicate the need for an interpreter ahead of time, adding time and logistical pressures when an interpreter needs to be requested at the time a patient arrives for their visit. In the last decade, literature on strategies to improve the accuracy and completeness of family history data and reduce time barriers to family history collection has focused on digital tools that can be utilized by the patient prior to their visit [39]. Web-based tools such as My Family Health Portrait [42] allow patients to gather information from their own records and in conversation with family members, but there have been concerns that digital and health literacy factors may limit the utility of these tools across diverse populations [43,44]. A randomized controlled trial of a more interactive virtual counselor "VICKY" (Virtual Counselor for Knowing Your Family History) showed promising results in terms of usability and efficacy for collecting family history, even among participants with limited health literacy [45]. In addition, the culturally and linguistically-adapted Spanish VICKY version was found to be usable and acceptable among a diverse population of Spanish speakers [46]. Even with consideration of the use of such digital tools outside of research settings, however, interpersonal communication between patients and providers/MAs at the time of the visit to expand upon or clarify information entered remains critical to collecting and refining family history collection, and our findings therefore add to this emerging literature.

4.2. Innovation

In summary, based on the findings from this study, we suggest the following innovations that can help improve the collection of more

comprehensive family histories, in particular cancer family histories, among Hispanic and Spanish-speaking patients. To improve communication with and care provided to Spanish-speaking patients, there is a need to increase healthcare provider awareness about implicit bias, to address ad hoc workflow adjustments within practice settings, and to evaluate the need for professional interpreter services even if some members of the healthcare team speak Spanish. Additional training for interpreters regarding family history vocabulary may also be needed to improve the accuracy of the family history information that is collected. To reduce gaps in family history collection for Spanish-speaking patients in primary care, we need improved tools, that are available in Spanish and culturally tailored, to facilitate intrafamily communication and enhance patient family health literacy. It is important to maximize information gathered at or before the first patient encounter, as this is where most effort for family history collection is focused. Healthcare practices can promote awareness and increased utilization of patient portals and integrate low-tech solutions that do not require internet access such as text messaging.

5. Conclusion

This qualitative study identified knowledge barriers, interpersonal communication barriers, and organizational barriers to family history collection for Spanish-speaking patients in primary care settings. Findings suggest that a key priority to enhance communication regarding family history and cancer family history with Spanish-speaking patients would be to standardize processes for working with interpreters. Increased use of existing EHR patient portals and enhanced bilingual online tools to facilitate family history collection in preparation for the visit may also be helpful, but their acceptability and usability will need to be evaluated for more widespread use among patients with limited English proficiency.

There were some limitations to our study design and recruitment. Our study did not include the patient perspective and involved a limited number of health centers in each health system. We were unable to do direct observation of the communication processes in collection of family history in these settings and relied on participants' reports of workflows and communication processes. This interview-only approach is likely to elicit normative scripts about how clinical processes work and potentially misses some details of real clinical workflows. Though we did not directly ask about the impact of the COVID-19 pandemic, the interview data did not suggest that COVID-19 impacted family history collection efforts or workflows.

Despite these limitations, our findings add to the limited literature on barriers to family history collection among Spanish-speaking patients and have important implications for addressing barriers to the use of family history as a tool for clinical recommendations and genetic services referral among patients with limited English proficiency more broadly. Online tools for family and patient history collection must be further evaluated in real-world clinical settings, with diverse patient populations. User-centered studies on patient portals, involving user input into patient portal functionality intended to accommodate non-English speakers, are needed. Strategies to increase utilization of patient portals must consider structural as well as individual barriers and facilitators, including internet and smart phone accessibility among the populations being served. Further research is also needed to evaluate the comparative efficiency, acceptability and quality of communication and care provided by bilingual providers or in collaboration with formal interpreters.

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Appendix A. Supplementary data

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