Rural Mexican-Americans' perceptions of family health history, genetics, and disease risk: implications for disparities-focused research dissemination

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Abstract Disseminating the results of transdisciplinary health disparities research will increasingly involve discussing family health history and/or genetic information with study participants and their communities. Often, individuals' familiarity and comfort with these topics will be unclear. To inform the dissemination activities of a Center for Population Health and Health Disparities (CPHHD) studying multilevel determinants of breast cancer disparities in Latinas, we talked with Spanish-speaking Mexican-Americans from a rural agricultural community about family health history, genetics, and disease risk. We found that participants had limited genetic literacy but were familiar with some concepts related to family health history. Participants emphasized the role of individual behavior in shaping health and expressed a strong desire for health-related information. This included genetic information about future disease risk, which participants were previously unaware of but thought could be useful for disease prevention. These findings suggest that for research dissemination to facilitate health promotion, gaps in knowledge, particularly genetic knowledge, will need to be overcome. Outreach to underserved Latino communities should take advantage of this existing knowledge of family health history and strong desire for health information, but also take care to not overstate the

significance of unreplicated or low-penetrance genetic associations.

Keywords Research dissemination · Transdisciplinary · Genetics · Family health history · Health disparities · Hispanic/Latino

Introduction

Many transdisciplinary research endeavors make an explicit commitment to the dissemination of their work as a means of research translation as well as to demonstrate reciprocity to study participants. These commitments are particularly important in initiatives that employ participatory research methods, work with underserved populations, and address societal problems such as health disparities (Emmons et al. 2008; Cooper et al. 2013). The Partnership for Understanding and Eliminating Disparate Outcomes (PUEDO) for Latinas, a transdisciplinary Center for Population Health and Health Disparities (CPHHD) at the Fred Hutchinson Cancer Research Center in Seattle, Washington, has among its research objectives the examination of ancestral genetic background and its relationship to breast cancer tumor biology and metabolic response to diet. Additional project aims involve characterization of risk factors for distinct molecular subtypes of breast cancer, including family health history. Dissemination of PUEDO study results may therefore involve discussion of genetic risk factors and family health history as they relate to risk of breast cancer and its metabolic precursors.

PUEDO investigators wanted to disseminate research findings to study participants as well as other Latinos living in Washington State, but wondered how findings related to family health history and genetic risk would be understood and acted upon, particularly among the growing population of

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monolingual Spanish speakers living in rural agricultural communities in Eastern Washington. Literature on Latinos' awareness and understanding of family health history and its relationship to disease risk is limited, with almost no research on recent immigrants who live outside of urban centers. There is some evidence suggesting that Latinos are aware that family health history can be a risk factor for disease and are familiar with family health history information being requested during health care interactions (Gibbon 2011; Vadaparampil et al. 2010). But, studies have also shown that the active collection of family health history within Latino families is rare (Centers for Disease Control 2004; Corona et al. 2013). Key factors shaping the collection and communication of health history in Latino families are unknown, although cultural influences on secrecy, stigma, fear, and family dynamics have been proposed as potential barriers (Corona et al. 2013; Kinney et al., 2010).

It is also unclear whether Latinos living in the USA recognize that family health history is used as a tool for assessing and managing health risks because of the information it provides about shared genetic and environmental factors (Valdez et al. 2010). The literature indicates that Latinos, particularly those from underserved communities, may not recognize that family health history is related to genetics (Ricker et al. 2007). Additionally, multiple studies have shown that Latino community members often have limited awareness and understanding of issues related to inherited risk for disease (Gibbon 2011; Kaphingst et al. 2011; Kinney et al. 2010; Vadaparampil et al. 2010). Latinos may also not understand risk in a genetic context because of limited genetic literacy, defined as the capacity to obtain, process, understand, and use genetic information (Eichmeyer et al., 2005; Lea et al. 2011). Low genetic literacy may be due to the limited access to health care and health information faced by many Latino communities in the USA (Ortega et al 2007).

To inform PUEDO's future work around results dissemination, the Ethics and Policy Core (EPC) conducted ten semi-structured interviews with Spanish-speaking Mexican-Americans from a rural agricultural community aimed at broadly exploring perceptions of family health history, genetics, and disease risk. Interview results will be used to guide efforts to develop written materials for use in the Center's ultimate outreach and dissemination activities.

Methods

The EPC developed an interview guide addressing PUEDO investigators' major dissemination concerns based on the knowledge gaps identified in the literature. The guide was revised based on feedback from PUEDO faculty and staff, including the Center's Principal Investigator and a Community Advisory Board (CAB) member, as well as an external

investigator with experience working with Latino communities. Topics covered in the interview guide included family communication, family health history, disease risk, and genetics. Excerpts from the interview guide, including guiding questions and suggested probes, are given in Table 1.

Ten pilot, one-on-one interviews were conducted in Spanish by a culturally matched *promotor* (community health worker) with a convenience sample of Latino adults recruited from the lower Yakima Valley in Washington State. The Yakima Valley is a rural agricultural community of Latinos who are primarily recent immigrants from Mexico. Participants were recruited through a National Cancer Institute (NCI) Community Networks Program Center (CNPC) based in Sunnyside, Washington, with extensive connections with the Latino community in the Valley. Participants had provided consent to be contacted in the future for other studies and were approached by phone and invited to participate in this study; there were no refusals. The *promotor* had extensive experience conducting interviews and underwent several trainings on interview techniques, qualitative data collection, and this particular interview guide. Interviews were conducted in person and were recorded, transcribed, translated by a bilingual translator, and reviewed for accuracy by a second translator. Both translators were of Mexican origin and have familiarity with linguistic variations in the sample population. Transcripts were analyzed by a single coder using conventional content analysis (Hsieh and Shannon 2005). As this was a pilot study,

Table 1 Interview guiding questions and follow-up probes, by topic area

Family communication

- About how often do you see your family or speak to them?
- What do you normally talk to your family about?
- Who do you normally talk to about your health?
PROBE: Family, friends, doctor?
- Do you talk with your family about relatives who have passed away?
PROBE: Do you about their health or what caused their death? How easy is it to do this?

Family health history

- Are there diseases that are common or run in your family?
PROBE: Do you think that makes it more likely that you will get those diseases?
- What does the phrase "family history" mean to you?
PROBE: Do you think it is important for people to know their family history of health and illness? Why or why not?

Genetics and disease risk

- What does "disease risk" mean to you?
PROBE: Why do you think that some people get sick and others don't?
- What does the term "genetics" mean to you?
PROBE: Do you believe that genetics or inheritance can affect your health?
- What are the most important things for your health?
- If genetics could tell you what diseases you might someday develop, do you think it would be helpful to get that information? Why or why not?
PROBE: Do you think getting this information would affect you or your family in any way?

no attempt to reach saturation was made. Codes, categories, themes, and their relationships were discussed by all EPC members throughout the coding process using peer debriefing and also presented to PUEDO investigators and the Center's External Advisors, who aided in results interpretation (Miles and Huberman, 1994). All study procedures were approved by the Fred Hutchinson Cancer Research Center Institutional Review Board (IRB), and informed consent was obtained from all interview participants.

Results

Table 2 provides demographic characteristics for the ten interview participants. As shown, the mean age of the interviewees was 44, with most having less than a high school education and an annual household income below 30,000 USD. All participants (six men and four women) reported being born in Mexico and speaking Spanish as their primary language; these participants had been living in the US for between 10 and 28 years.

Key themes identified from the interviews were grouped into three main content areas: beliefs and practices around family health history, understanding and interest in genetics, and taking personal responsibility for health (Table 3).

Beliefs and practices around family health history

Participants were familiar with the concept of family health history and its relationship with disease risk (theme 1). One participant illustrated his understanding, saying, “To me family history means knowing what diseases our parents, siblings, and other relatives had and that way knowing how prone one is to acquiring that disease.” All interview participants believed that knowledge of family health history was important for disease prevention (theme 2). One female participant

Table 2 Demographic characteristics of interview participants ($n=10$)

	No.	Mean (range)
Gender		
Male	6	
Female	4	
Born in Mexico	10	
Spanish primary language	10	
Annual household income		
<\$15,000	1	
\$15,000–\$30,000	6	
\$30,000–\$45,000	3	
Age		44 (34–54)
Years in USA		19 (10–28)
Years of education		8 (2–12)

Table 3 Perceptions of family health history, genetics, and disease risk: themes by major content areas

Beliefs and practices around family health history (FHH)
1 Familiar with FHH and its relationship with disease risk
2 FHH important for disease prevention
3 Discussion of FHH varies by family dynamics and disease type
4 Families talk about general health, not disease specifics
Understanding and interest in genetics
5 Limited genetic literacy
6 FHH not connected to biological inheritance or genetics
7 Genetics has limited role in determining health status and disease risk
8 High interest in personalized genetic risk information
9 Genetic risk information would help one prepare for the future
Taking personal responsibility for health
10 Strong desire for health information
11 Emphasized personal responsibility for health, lifestyle factors, and individual behavior
12 In general, health promotion not a priority for Latinos

described the need for vigilance based on family health history in this way:

So, [with family health history] one can personally get an idea—like for example, say now, if my mom has heart issues, like I at times suffer from high blood pressure, because of that I have to keep checking. Or if my dad had bad blood circulation or if he had gout, or if my brothers, the ones who died, one has to really know what that is.

Everyone that we interviewed was in contact with their extended family, most of who lived in Mexico. Many participants spoke to these family members at least once a week on the phone. The frequency with which family health history was discussed appeared to depend on family dynamics and vary by disease (theme 3). Although all of the participants stated that they were comfortable sharing personal health information within their family, they claimed that most Latinos were not. Interviewees gave different reasons that Latinos would choose not to discuss their health with their family including embarrassment, e.g., “not all of them talk about diseases because many are embarrassed or don't want others to know what they have,” and denial, e.g., “we [Latinos] don't want to accept that we have a disease.” A number of participants also proposed that having a stigmatizing condition, such as a sexually transmitted disease or a disease affecting the reproductive system, would impact willingness to discuss it openly within the family. Finally, although health was described as a common topic of conversation within our participants' families, they also told us that they typically did not know specific details about what caused their relatives' deaths (theme 4).

Understanding and interest in genetics

The participants we spoke to had limited genetic literacy; for example, none could describe what “genetics” meant to them in their own words (theme 5). Although many participants thought that they were at higher risk for a disease if it ran in their family, they did not connect this increased risk to biological inheritance or genetics (theme 6). Family history, in the words of one female participant, “...is not about inheritance, it’s about how you live, how you take care of yourself, how you eat.” When asked why some people get sick and others do not, genetic factors were never mentioned without prompting and appeared to have limited relevance to our participants’ views of health status and disease risk (theme 7). Another female participant explained:

If one has an organized life, healthy and eats healthy, it [genetics] may affect it [health], but not only having the inheritance. It’s taking care of ourselves, doing exercise and eating healthy.

In contrast, when we raised the prospect of genetic testing during the interview, interest in genetic information about future risk of disease was high (theme 8). All participants affirmed the belief that “genetic information telling you what diseases you might someday develop” would be more helpful than simply knowing what diseases ran in their family. Many stated that this type of genetic risk information would allow them to prepare for the future (theme 9). One woman explained her interest in receiving personalized genetic risk information, saying, “...that way I’d know more about what to prevent and how to be prepared. I would look for more information about what I could be suffering from.” Very few participants thought that knowing their genetic risk factors would have adverse psychological effects. Those who did express concerns were wary of learning about what may happen to their health in the future.

Taking personal responsibility for health

A strong desire for health information of any nature was apparent throughout the interviews (theme 10). Participants repeatedly stated that they wanted information that could help them lead healthier lives. One man told us that, “...it’s much better with more information; I feel better.” This interest in health information appeared to be motivated by a view of health that emphasized personal responsibility. The most important factors shaping health, in the words of one woman, are, “To sleep a minimum of eight hours per day, to have a relaxed life, to eat healthy, fruits, vegetables three, four times a day, not to smoke, not drink, and do exercise at least three times a week.” Differences in health status were always attributed to differences in lifestyle factors and individual behavior

(theme 11). As explained by one male participant, “...some people get diseases and others don’t because they take better care of themselves, they eat healthier and do more exercise.” Thus, interest in learning about future disease risk through personalized genetic information was in line with participants’ overall desire for information that would allow them to take action, be accountable, and improve their health as individuals.

Finally, while it was clear that taking personal responsibility for health was important to our participants, they believed that, in general, it was not a priority for Latinos (theme 12). For example, one woman told us that most Latinos do not know their family health history because, “...they don’t take care of themselves and they don’t—they’re not interested and don’t say anything.” It appeared that some participants’ exposure to messages about diseases disproportionately affecting Latinos, their risk factors, and the role of health behavior contributed to their perceptions of Latinos as less health-conscious than other groups. Another female participant told us:

...most of the time it’s said that us Mexicans are the ones who do not know how to take care of ourselves, that we eat a lot of grease, that we don’t eat right. For me it’s all the same. Whether you’re Mexican or whatever, it all depends on what you eat at home....how you educate your children and the way they should eat.

Our participants frequently reminded us that Latinos “are not all the same,” but also described their interest in health promotion, ranging from collecting and communicating family health history to exercising and eating right, as atypical for many Latinos.

Discussion

These preliminary observations, from a modest sample of Spanish-speaking Mexican-Americans from a rural agricultural community, have a number of implications for PUEDO’s ultimate dissemination efforts, as well as the dissemination of other disparities-oriented transdisciplinary research initiatives that include a focus on inherited disease risk. For our CPHHD, they suggest that desire for health information may be a potent gateway to providing education about family health history and genetics that will be necessary to effectively communicate study findings back to participants, their families, and the broader Latino community in Washington State. The concept of family health history may help explain both genetic and inherited risk, although it is clear from our interviews that additional clarification of these concepts and the role of family health history and/or genetic testing in risk assessment and disease management will be needed (Kaphingst et al. 2011).

Our participants reported being comfortable talking about health with their families but mentioned stigma, denial, and embarrassment as reasons that Latinos, in general, may not be. Similar barriers have been found in other sociodemographic groups (Hovick et al. 2015; Klitzman et al. 2007; Mellon et al. 2006). This reminds us that there may be more diversity with respect to family dynamics and health communication preferences within social and cultural groups than between them (Kleinman and Benson 2006). Finally, we observed that our participants' family conversations about health usually did not include information about the disease, its age at onset, or its severity, which would be important for a clinically useful family health history. These findings align with those of previous studies and suggest that additional work is needed to increase Latinos' awareness and understanding of family health history as a specific clinical and public health tool (Corona et al. 2013; Kaphingst et al. 2011).

Many CPHHDs, including our own, are studying genetic determinants of disease to better understand the multilevel factors contributing to health disparities and improve our ability to intervene and narrow outcome gaps between groups (Warnecke et al., 2008). While genomic research can provide important insight into disease biology, with the exception of a few high-penetrance genetic diseases with well-validated preventive interventions (e.g., *BRCA1/2* mutations and hereditary breast and ovarian cancer), most genetic and genomic applications currently have limited or unknown clinical utility (Bradbury et al. 2014). This reality, coupled with the low genetic literacy we observed in these interviews, suggests that we should take care not to overstate the significance of any unreplicated or low-penetrance genetic associations and possibly contribute to hype in a population hungry for health information. Clarifying the differences between aggregate genetic results and personal genetic results, and the probabilistic nature of both, as well as the differences between novel and well-validated genetic findings during dissemination may also pose a challenge (Eichmeyer et al. 2005). It is also unclear whether learning aggregate genetic findings will influence the beliefs about personal responsibility for health that our participants expressed and potentially impact their health behavior. There was limited evidence that information about genetic risk factors would be interpreted fatalistically, although the interviews did not specifically explore that hypothesis. Additionally, participants saw few potential negative implications of learning about genetic risk factors for either themselves or their families. These results diverge from previous research with more highly acculturated Latinos living in urban areas and deserve further study in larger samples (Thompson et al., 2003). Finally, care should be taken to avoid presenting genetic risk factors that may occur at higher frequency in Latino populations as deterministic or "abnormal" (Lee et al. 2008). This could contribute to genetic essentialism and potentially compound the negative perceptions of

Latinos' health status and health behavior practices that we observed during some of the interviews (Dar-Nimrod and Heine, 2011).

This study has several limitations that are important to note. First, and perhaps most importantly, this was only a pilot study. Thus, our sample was small and included primarily lower socioeconomic status Mexican-Americans with low levels of acculturation. Additionally, the interviews were conducted with a convenience sample recruited through an established health promotion center in a single community, although participants had not previously participated in genetic research and were sociodemographically similar to the larger Latino population in Eastern Washington, who are a primary audience for PUEDO's ultimate dissemination efforts. Still, these findings should not be considered representative or generalized to other Hispanic/Latino populations. The themes related to family health history, disease risk, health, and genetics that were observed in this small sample should be confirmed in other Latino communities, and potential variation by factors like gender, acculturation, country of origin, and health care access should be explored.

These interviews highlight the importance of identifying and engaging the target audience before beginning research dissemination. They also reinforce the major gaps in knowledge and perceived relevance that may need to be overcome to effectively translate results from transdisciplinary initiatives and close outcome gaps between advantaged and disadvantaged groups (Viswanath and Finnegan 1996; White et al. 2009). Our findings suggest that this will be particularly true for health promotion activities that involve communication of risk information based on family health history or genetic factors to underserved and low literacy populations, including many Latino communities. These already disadvantaged groups would bear the additional burden of any unintended or negative effects (Hovick et al. 2014; Sussner et al. 2013). One way to address this issue is to include the target population throughout the research and dissemination processes—a key tenant of community-based participatory research (CBPR) approaches (Cashman et al. 2008). To this end, PUEDO will continue to go back to former participants and Latino community members as we move forward in the dissemination process.

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Compliance with ethics guidelines All human subjects research was approved by the Fred Hutchinson Cancer Center Research Center's IRB and is in full compliance with the current laws that protect human subjects in the USA.

Conflict of interest The authors have no conflicts of interest to declare.

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