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Where culture meets genetics: Exploring Latina immigrants' lay beliefs of disease inheritance

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ABSTRACT

As medical genetic services become a standard part of healthcare, it will become increasingly important to understand how individuals interpret and use genetic information. Exploring lay beliefs of disease inheritance that differ along cultural lines is one research strategy. The purpose of this study was to describe conceptualizations of disease inheritance held by members of the Latina immigrant population in the United States. Semi-structured interviews were employed to gather qualitative, exploratory data from 20 Latina immigrant women. All interviews were conducted in Spanish, and thematic analysis was used to analyze interview transcripts. Demographic and acculturation data were also collected and analyzed. The final sample was diverse in age, time lived in the United States, country of birth, and education level. From participant interviews, the authors identified one dominant model of disease inheritance to which most participants ascribed as well as two non-dominant models. The main model was characterized by a focus on the ability to modify an underlying disease risk, especially in the case of hereditary predisposition to common complex disease. Of the non-dominant models, one focused on genetic disease as extraordinary and less modifiable while the other placed less emphasis on the role of genes in health and greater emphasis on non-genetic factors. Across these models, participants expressed their uncertainty about their understanding of genetics. Many of the themes that arose from the interviews, including uncertainty in their own understanding of genetics, were similar to those seen in studies among other populations. Importantly, participants in this study demonstrated a lack of genetic fatalism, which may allay fears that explaining the role of genetics in common health conditions will reduce uptake of positive health behaviors. These findings have practice implications for healthcare providers communicating genetic information to Latina immigrants.

1. Introduction

As genetic services become a standard part of healthcare, it will become increasingly important to understand how individuals interpret and use genetic information. When people are given genetic information, they naturally evaluate it in the context of their own lay beliefs about genetics and inheritance. Shiloh (2006) notes that individuals generally acknowledge genetics as a cause of illness in studies of causal attributions. However, what genetics or inheritance means to people may vary (Shiloh, 2006).

Studies have documented cultural and racial differences in beliefs about inheritance. One focus group study found that African Americans perceived a higher risk associated with a hypothetical "gene for heart disease" than did European Americans, and African Americans were also more likely to perceive the consequences of such a gene as being death or premature death (Bates et al., 2003). In a separate focus group study, both African American and European American males indicated less genetic influence on height than females did, and African American women perceived a greater role of genes in breast cancer than European American women (Parrott et al., 2003). Finally, a study of British-Pakistani families referred to a UK genetics clinic identified culturally grounded beliefs about genetics, including the idea that first-cousin marriages did not cause disease and that children receive most or all of their genetic material from the father (Shaw and Hurst,

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2008). These studies provide evidence that race, culture, and gender may inform lay beliefs about disease inheritance.

Latinos are currently the largest minority group in the United States and have significant health disparities including in type 2 diabetes and breast cancer (American Cancer Society, 2014; Cersosimo and Musi, 2011) both of which can be influenced by genetics. Nevertheless, Latinas are less likely to utilize genetic services and more likely than their non-Hispanic white counterparts to decline certain genetic tests, such as amniocentesis (Browner et al., 2003; Levy et al., 2011). Previous studies have identified areas of miscommunication between Latina clients and healthcare providers (Browner et al., 2003; Joseph et al., 2017; Joseph and Guerra, 2014). Studies of Latinas' attitudes towards genetic testing in regard to cancer risk have found that awareness of genetic testing among Latinas is low but that attitudes tend to be very positive once awareness is raised (Hamilton et al., 2016; Kinney et al., 2010; Ricker et al., 2007; Sussner et al., 2015, 2013). While this research has shed light on some of the causes of disparate uptake of genetic services among Latinos, none has explored the lay beliefs of Latinos about genetics and disease inheritance. Understanding these beliefs will be essential to decreasing the barriers Latinos encounter around genetic services, such as lack of awareness and miscommunication.

A challenge to any study of Latinos is the diversity of this group. Individuals in the US who identify as Latino may have been born in this country or in one of 33 distinct nations and may speak Spanish, Portuguese, English or a native language. Beliefs about genetics may be influenced by any of these or other factors. Obtaining a sample large enough to identify differences between these groups would be a herculean task. Consequently, our study focused on one subset: Spanish-speaking Latina immigrant women. There is evidence that health disparities are worse among Latinos with lower acculturation, often measured by language preference, and that causal beliefs may be shared among Latina immigrants but differ from those of US-born Latina women (Cersosimo and Musi, 2011; Chavez et al., 1995). Men and women may also have differing beliefs about the role of genetics (Emslie et al., 2003; Parrott et al., 2003), and women are often the caretakers in Latino families and have the most knowledge of healthcare (Caballero, 2011). Therefore, this is an important subset of the population to understand. Consequently, this study sought to describe the lay beliefs of disease inheritance held by Spanish-speaking members of the US Latina immigrant population.

2. Methods

2.1. Participants

Eligible participants were women over 18 who self-identified as Latina, currently lived in the United States, had been born in Latin America, spoke Spanish, and were available for an in-person interview in the DC, Maryland, northern Virginia (DMV) area. Data on participants' beliefs about disease inheritance were collected as part of a longer interview or series of two interviews that also asked about participants' causal attributions of breast and colon cancer (data to be published separately). To obtain a population with similar personal experiences of these cancers, individuals with a personal history of breast, ovarian, or colon cancer were excluded.

Participants were recruited via the National Institutes of Health (NIH) Clinical Research Volunteers Program (CRVP), ResearchMatch, and other existing research protocols at the NIH Clinical Center. The NIH CRVP (https://clinicalcenter.nih.gov/recruit/volunteers.html) is a registry of individuals interested in participating in research studies at the NIH. ResearchMatch (researchmatch.org) is "an online, national clinical research registry that 'matches' people who want to participate in clinical studies with researchers who are seeking volunteers." Members of the research and medical staff at the NIH were excluded from participation since the purpose of the study was to identify and explore lay models of disease inheritance. Purposive sampling was employed to select for participants with diverse education levels. The first author requested a spreadsheet of all female volunteers self-identifying as Hispanic/Latina, over age 18, in the DMV area who had registered with the NIH CRVP from January 2014 to August 2016. The first author contacted individuals included on this list, explained the research project, and assessed interest in participation. Concurrently, she used the ResearchMatch database to send an e-mail message to eligible women within 50 miles of the NIH Clinical Center. Interested individuals could choose to allow the team to contact them. Finally, additional recruitment was conducted through existing protocols at the NIH Clinical Center. In this case, a qualified researcher of the collaborating protocol recruited eligible individuals to the study. All recruitment and data collection occurred between June and August of 2016. This study received ethics approval from the National Human Genome Research Institute Institutional Review Board.

2.2. Data collection

The first author carried out all recruitment, screening, and interview procedures. Upon initial contact, participants were asked a series of questions to determine their eligibility for the study based on the criteria described above. Once eligibility and desire to participate were confirmed, the participant and the first author would find a mutually agreeable time and location for the in-person interview. Interviews were conducted in reserved rooms at local public libraries or at the NIH.

The initial study questions and interview guide were tested in three pilot interviews with women meeting all eligibility criteria but recruited from a local Latino health center. These pilot interviews were used to assess the clarity of interview questions, incorporate additional questions, assess the ease of completing the interview, and estimate the time needed to complete the interview. The interview guide and study procedures were modified based on pilot interviews.

All interviews were conducted in Spanish following a semi-structured interview guide, recorded, and later transcribed by a third-party transcription service. The interviewer shared and reviewed the consent document with each participant and obtained verbal consent prior to starting each interview. At the start of the interview, participants answered demographic questions regarding country of birth, age, age at immigration to the US, years lived in the US, highest level of education completed, and any other languages spoken, as well as four questions on language use from the shortened version of the Short Acculturation Scale for Hispanics (SASH) (Marín et al., 1987). Participants were asked to share information on any family history of cancer then complete the section of the interview related to casual attributions of breast and colon cancer (data to be reported separately).

The section of the interview regarding beliefs about disease inheritance began by asking the participant to mention everything that came to mind when hearing the word 'genetics.' Next, participants were asked about how they think genes influence health and other open-ended questions regarding the participant's experience with and beliefs about disease inheritance. Questions were asked about types of diseases that are inherited, how inheritance of disease occurs, whether the participant feels there are inherited diseases in her family, and the perceived preventability or controllability of inherited disease. Any unanticipated themes or information were noted for analysis and some were used as probes in future interviews. Interviews ranged from approximately 30 to 70 min and averaged 50 min. Recruitment and data collection continued in tandem until thematic saturation was reached. Each participant was offered a $20 gift card for each interview.

2.3. Analysis

All interviews were transcribed verbatim in Spanish, and transcripts were uploaded into the qualitative analysis software Nvivo for Mac version 11.3.2 and later 12.0.0. The first author derived the codebook and conducted all coding of the interview transcripts. This approach was

based on the anthropological tradition that only individuals involved in the interview process be involved in the coding and analysis of interviews since knowledge gained during interviews and in interacting with participants is not easily conveyed to a post-hoc second coder (Morse et al., 2002). Using thematic analysis, an initial codebook was devised based on both structural and content coding (Guest et al., 2012). In developing the codebook, the first author started with codes for themes that arose throughout interviews as recalled and recorded. In addition, codes were added for each standard interview guide question. This allowed for organization of the data from the transcripts by topic and identification of emerging themes from further analysis within each topic. The codebook was revised iteratively, and new codes were added, changed, and deleted according to the data. These additional codes were identified during the coding process. Any new codes were retroactively applied to previously coded transcripts, and the final codebook was applied to all interviews.

3. Results

3.1. Population

A total of 20 women completed the interview. Participants' countries of origin spanned all regions of Latin America. Nearly two-thirds of the sample was classified as being of a low level of acculturation. See Table 1 and Figs. 1 and 2 for a complete summary of participant demographic characteristics.

3.2. Conceptualizations of disease inheritance

From the interviews, three lay models emerged. We have deemed the dominant model the "Modifiable Genetic Risk Model" (MGRM) (Fig. 3). While most participants described genetics and disease inheritance in a way that fit with this model, a minority of participants' descriptions were grouped into two additional models: the "Extraordinary Genetic Disease Model" (EGDM) and the "Peripheral Genetic Risk Model" (PGRM). Thirteen participants described the MGRM while four participants ascribed to the EGDM and three to the PGRM. While each of the alternate models had overlap with the MGRM, and some participants describing these other models may endorse certain features of the MGRM, their overall explanations of disease inheritance did not map onto the more common model.

3.2.1. Modifiable Genetic Risk Model (MGRM)

3.2.1.1. Genes and health. In the MGRM, participants described genetics as a very integral part of the person, underlying everything about the individual. This was often through the use of colorful metaphors of genetics as a map or book, as seen in comments by P101:

> "I think that [genetics] is like a map. A map of how one is built, how you're built, and then how you are going to-a map of what you can expect in terms of diseases. In everything."

Here P101 expresses the idea that genetics can serve as a guide and can even help people predict their future health. Participants commonly discussed genetics as important in many aspects of health.

Table 1
Demographic characteristics of the study population.

Characteristic	Range	Mean (SD)
Age (years)	21–57	39.1 (9.53)
Age moved to the US (years)	3–46	24.2 (12.5)
Years lived in the US	2.5–27	14.6 (7.89)
Acculturation Level		
Low	13	65.0%
High	7	35.0%

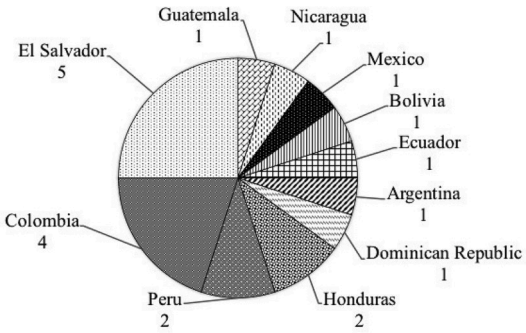

Fig. 1. Participant country of origin and frequency.

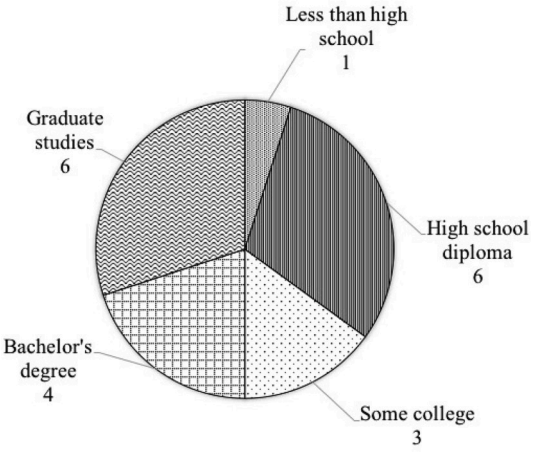

Fig. 2. Participant education level and frequency.

> "I think that cancer is [hereditary]. Other illnesses, I don't know, like diabetes, like heart problems, I think that many illnesses are linked to the hereditary factor." (P101)

This quote also shows that when asked specifically about any genetic conditions in their families or asked what illnesses they think of when they think of genetic disease, participants who ascribed to the MGRM most commonly referred to common complex diseases, rather than more traditionally Mendelian genetic conditions. As seen here, diabetes was a condition that participants frequently mentioned as a genetic disease in describing the MGRM. In fact, diabetes seemed to be the most salient genetic condition for many of these participants, often being the first or only genetic condition listed.

3.2.1.2. Modifying disease risk. The core principle of the MGRM is the idea that one's risk of genetic disease can be modified by one's lifestyle. Participants endorsed this ability to modify disease risk to varying degrees, but most of the women felt that a genetic disease was even more preventable than a non-genetic disease because the individual had the opportunity to know the risk and take preventive action. This can be seen in the following quote by participant P109:

> "[Genetic disease] must be more preventable because you can prepare yourself. If I know that everyone on my father's side and my mother's side has diabetes, I can eat healthier things that don't have a lot of sugar, do more exercise, eat things that don't have a lot of sugar like Coca-Cola."

Here, P109 explains how family history could motivate positive health behaviors, making hereditary illness more preventable. Participants mentioned various ways to prevent illness or modify a genetic disease risk including exercise, taking care of oneself, and regular

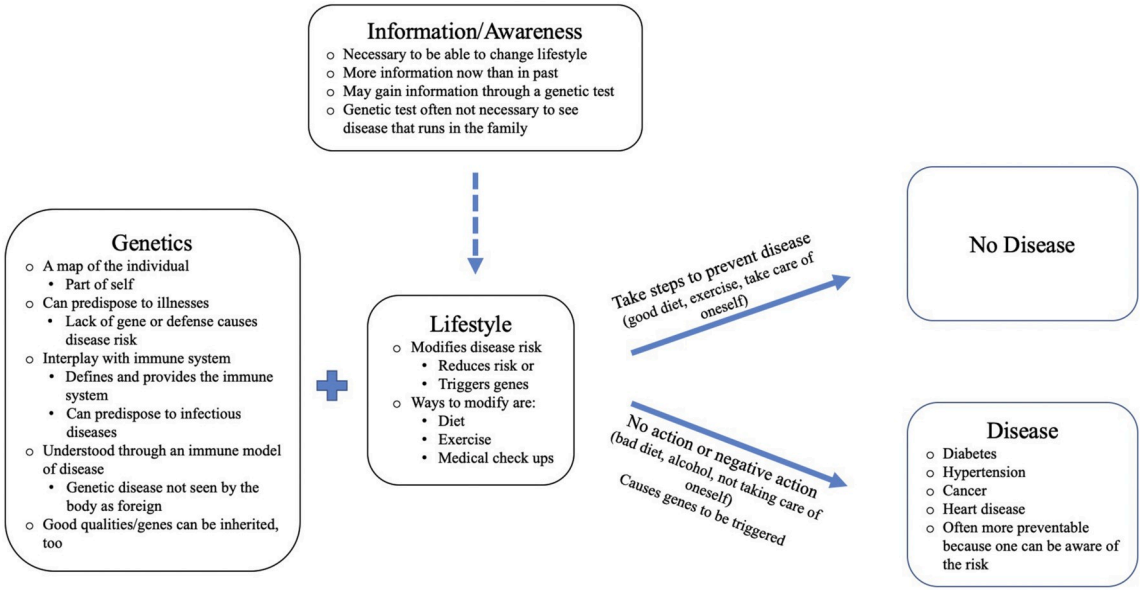

Fig. 3. Diagram of the Modifiable Genetic Risk Model Fig. 3 provides a visual representation of the Modifiable Genetic Risk Model. Genetics, including a genetic disease risk, interacts with one's lifestyle to either produce or prevent disease. Information and awareness about how to prevent disease is necessary for individuals to modify their lifestyle appropriately. Lifestyle can then either include actions to prevent disease or inaction or negative actions that trigger disease.

medical checkups, but the most frequent way mentioned was through diet, as shown in the quote above and in the following comments by P205:

> "Each person should know what they should do to prevent what they already bring in their genetic load. For example, I know that my dad died of colon cancer. I'm on top of my colonoscopy. I have a good diet in which I avoid fat and red meat."

Here, P205 again directly references her family history and how that influences her health behaviors. She talks about screening but also focuses on dietary changes. It is possible that the strong focus on diet as a way to mitigate genetic risk is because women commonly thought about diabetes as a hereditary disease, and this condition can often be prevented or controlled through diet and exercise.

For many participants who ascribed to the MGRM, the flipside of being able to prevent genetic disease through positive lifestyle was the idea that negative environmental or lifestyle factors could set off a "dormant" genetic condition.

> "I say that we can have genes that are there, like hidden, not hidden but that are asleep, so any activity can, an external impact can trigger them." (P105)

These contrasting themes of prevention and triggering reflect an idea that genes, lifestyle, and the environment interact to produce or prevent disease. According to participants, genes lie underneath the surface, and actions, such as eating well, can protect against or mitigate the effects of genetics. However, actions and things encountered in the environment may "set off" the genes and cause illness. While participants saw a role for genetics in many traits, they did not see genetics as fully determining these traits.

An important part of the ability to modify disease risk is knowing that one is at risk. Being aware of the illnesses in one's family and having knowledge of ways to modify the risk were important themes discussed by participants regarding prevention of disease. Some participants who ascribed to this model mentioned genetic testing as a means of identifying disease risk. More often, participants talked about simply seeing the disease run in the family. Importantly, some participants made a contrast between their access to health information and that of previous generations or those still living in their country of origin, which can be seen in this part of the interview with P108:

> "sadly, in my family in those times there wasn't much information. There wasn't much education about health, so I think without proper education they ate … and part of the culture that plays a role in these countries, that the more fried the food, the tastier, the healthier in those times that was the thing, so I think that all that influenced my mother to develop that type of disease, diabetes, and she didn't take care of herself, but I think there was no information, she didn't know what she had to do with her own body"

In this explanation, P108 talks about seeing a disease in her family but also gives an explanation for that disease that is based in a different time, place, and culture. By highlighting the beliefs and customs of the past, she implies that today there is information that can prevent the diabetes that her mother developed.

3.2.1.3. Method of inheritance. Not all participants whose descriptions mapped onto the MGRM described a method of genetic inheritance of a disease. Those who did, often spoke only generally about inheriting a "genetic component" without providing additional detail. Some described that genetic component as the absence of a necessary genetic factor.

> "For example, people who can't move, they're born and they can't move, that's because they're missing such-and-such gene." (P203)

This way of thinking about the means of disease inheritance seems to have been partly tied to thinking about genetic inheritance through the lens of germ theory. Some participants attempted to use the model of the immune system fighting an infection to explain susceptibility to genetic disease.

> "Because if it's not genetic and you detect it in time, your body maybe could respond better, but if your body already, if your family genetically has acquired it, … I think the body is more predisposed to 'it's okay' and isn't going to fight for that, it isn't going to show symptoms as soon as when it is not genetic, that it will feel that it's something unknown and it will fight … your antibodies will try to defend you." (P212)

In the quote above, the participant utilizes an interesting

combination of both vocabulary and concepts from germ theory to describe disease inheritance. Here, the family becomes the patient, so instead of an individual acquiring an infectious disease, she talks about a family acquiring a genetic disease, which influences whether the body recognizes an illness as foreign or as part of the self.

Another way in which participants invoked the immune system to explain genetic predisposition was by explaining that genes are responsible for the strength or weakness of the immune system. This is seen in the following excerpt from P201:

> "Well [a cold] is caused by viruses but I think that our genes, if our immune system isn't very strong, viruses attack us harder, so I think that our immune system is controlled by our genes. So, it's related."

In this example, even infectious diseases, which most women identified as not-genetic, could be influenced by genetic susceptibility to or protection against infection. In keeping with the idea that disease inheritance is through failure to inherit something good, several participants also discussed the fact that good characteristics ranging from good health to intelligence to upbeat personality could also be inherited.

> "Well, if you have the good genes from your families, you're going to have a healthy life …" (P106)

In this discussion of "good genes," P106 implies that both good and bad genes can exist in one family, again indicating that having a family history of an illness does not guarantee that one will develop the illness.

3.2.2. Extraordinary Genetic Disease Model

The Extraordinary Genetic Disease Model (EGDM) characterizes the beliefs of participants who spoke about genetic illness as distinct from other areas of health. Participants who described the EGDM tended to use more specific vocabulary to talk about genetic illness. For example, the only participant to give a detailed description of autosomal recessive inheritance ascribed to this model as did the only participant to use the word "mutation" in talking about genetic disease.

> "Well, there are some [diseases] that are caused by mutations in the genes, like Down Syndrome, in fact there is a test that they do on pregnant women." (P107)

In this instance, P107 also demonstrates that when asked about genetic conditions, participants in the EGDM focused less on common complex diseases and spoke more about rare conditions, such as Down syndrome, malformations, and spina bifida. These participants also felt there was less opportunity to prevent a genetic disease or to modify the disease risk because of the strength of genes in dictating health. This is seen in comments by P107:

> "If it is genetic, it will influence a lot the way in which you develop the illness. And even when you protect yourself with things, I mean, if you avoid these things, preventing that cancer will be very difficult, because it was in your family already, or it was a genetic factor already … So, there is something really strong in the genetics for these illnesses."

This is in contrast to the way participants discussed prevention of genetic diseases in the MGRM. In the EGDM, genes are so strong, and genetic illness is so extraordinary, that prevention is very difficult.

In keeping with the model, participants who ascribed to the EGDM said that diabetes was not a genetic disease since diabetes does not fit the idea of a rare condition.

> "I think like diabetes, I think those are not genetic … But like with diabetes that is a personal decision, one knows what one eats and all that." (P208)

The above quote from P208 also shows that because these participants did not see diabetes as genetic, they thought that diabetes risk could be modified. This excerpt also shows the extent to which participants in the EGDM placed responsibility on the individual for their own health. In the case of diabetes, the MGRM and EGDM models overlap in seeing diabetes risk as modifiable but diverge in the underlying ideas about causation.

In contrast to participants who endorsed the MGRM, participants who ascribed to the EGDM spoke more frequently about the need for genetic testing to identify a genetic condition and less about simply seeing the condition running in the family, as seen in the words of P209:

> "Maybe people that have a family history of that illness, they could have genetic tests to avoid specifically that they or their children or their grandchildren get that illness."

Here P209 discusses family history not as the ultimate way to know about a disease risk but as information to guide genetic testing in order to prevent the disease in future generations. She reinforces the idea that a genetic disease cannot be prevented just with lifestyle modification but requires the "extraordinary" step of genetic testing.

3.2.3. Peripheral Genetic Risk Model

The final model we identified was the Peripheral Genetic Risk Model (PGRM). In this model, genetics was not a central component to participants' understanding of disease causation. When asked if they had any additional comments or even in discussing genetics in health, these participants brought up other explanations for disease. Specifically, these explanations were not infection or lifestyle but rather explanations outside the paradigm of Western medicine, as seen in the quotes below:

> "I think there are some illnesses that develop because of how you are on an emotional level. I mean, like you have more of an emotional cause and that comes and provokes a more physical illness." (P106)

> "I believe that 60% is more due to – More. 75% your mentality, for you to accept yourself with your mind. Because I think, your mind rules your body … mentally one is capable of breaking barriers." (P213)

> "Sometimes people say that they're curses [that cause alcoholism], but – and things like that, but only God knows." (P214)

In the first two quotes above, we see participants expressing the idea of "mind over matter." They differentiate between the cognitive/emotional and the physical and see the physical as an expression of what is happening in the mind. In the last quote, the participant draws heavily on spiritual explanation of illness but does not worry about knowing the actual cause as she leaves it up to a higher being.

Participants who described this model struggled more than other participants to express their beliefs about the role of genetics in health because they seemed more conflicted about the nature of their beliefs. Some, like P213, seemed to be working through their conceptualizations of genetic disease in the interview:

> "I think alcoholism is hereditary. My father was an alcoholic and my brother, no matter what we do—but—well, there are things that are contradictory, right? Because I am raising my brother's child, I took him when he was little. And depending on the education, I think I have educated him that – 'what are the consequences of being alcoholic? What are the consequences of doing drugs?' So, I think it could be hereditary, but if you find someone that leads you to not do it, you can break that chain. I mean, there is a contradiction there. Personally, for me, there is a contradiction … So there, what's hereditary goes against what one can cut off."

Here the participant herself recognizes contradictions in her thinking as she struggles to rectify her ideas that alcoholism is hereditary but is also informed by education. In this case, the participant's difficulty stems from her lived experience and is likely informed by her emotional reactions to this experience. Explaining alcoholism as hereditary removes blame from her father and brother for their disease and also

from herself and her relatives for not being able to help them. On the other hand, she needs to believe that factors outside genetics can modify that predisposition in order to hope that her nephew will not suffer the same illness. Interestingly, the three participants whose descriptions fell into this model were also the only three who discussed alcoholism in their families or close friends, as seen in two of the quotes above.

3.2.4. Overarching themes

Some themes that arose in the interviews did not seem tied to any one set of beliefs. One such theme was that of diabetes. Participants from all three models mentioned diabetes. In fact, 15 of the 20 participants raised the issue of diabetes during the interview. As described above, the way participants talked about diabetes and genetics differed based on the broader model. Nevertheless, this highlights the salience of diabetes in this population.

Another theme that cut across models of disease inheritance was uncertainty about participants' own understanding of genetics. Despite their ability to discuss conditions they view as hereditary in their families or in the general population, many did struggle when asked what they think of when they think of genetics or how to explain genetics to another person. About a third of respondents had difficulty providing any answer, while others who were able to answer, lacked confidence in their responses. Although many participants demonstrated reasonable familiarity with basic genetic concepts, they seemed generally insecure in their genetic knowledge. This was evident when asking participants what they associate with the word "genetics":

> "What words come to mind? Genetics. Nothing … Like it's in your blood, what's in your blood, right?" (P104)

> "The most colloquial way that I would put it is like … you're a miniature version … well for a child … you're a version, a mixed copy of your parents with a … Yes, a mixed copy of what your parents are, in what they are … I don't know how to explain, genes. A lot of major characteristics of your body." (P107)

These two participants demonstrated differing levels of detail, but both showed uncertainty. This uncertainty was not based on education level, as even participants with graduate level education expressed uncertainty.

4. Discussion

This qualitative interview study adds to the scientific literature by exploring the lay beliefs of genetics and disease inheritance among Spanish-speaking Latina immigrant women in the US. Our interviews with 20 Latina immigrant women revealed that these beliefs coalesced around one dominant model of disease inheritance characterized by a focus on genetic risk of common complex disease that participants felt could be modified by lifestyle factors, especially diet. Two non-dominant models of disease inheritance were also described by a minority of participants, one of which focused on genetic disease as very different from other health conditions and less preventable. The other model focused less on the role of genetics in health and more on other causes of disease, such as emotions and the power of the mind.

These three ways of conceptualizing the role of genes in health had overlapping features but also important differences. The fact that we identified multiple distinct ways of thinking about disease inheritance indicates that there is diversity in these beliefs among Latina immigrants, and these beliefs may not be influenced by an underlying cultural model. However, no demographic factors within our sample correlated specifically with any one model. The only possible relation was among those who ascribed to the PGRM who also all spoke about alcoholism, but how this may be related cannot be determined from our data. Uncertainty in their own genetic understanding was a common theme expressed by participants across models.

Significantly, the characteristics of the lay conceptualizations of genetics identified in this study were very much in line with those described in studies in other populations. For example, most participants were familiar and comfortable with the idea of both traits and health conditions running in families in keeping with McAllister's (2003) idea that all individuals are naïve geneticists and that "some knowledge about the inheritance of physical characteristics, personality and illness is part of family culture" (McAllister, 2003). The idea of illnesses running in families is not new to this population.

Even participants' uncertainty about their understanding of genetics and struggle to articulate how inheritance works has been seen across studies with a variety of populations (Correia et al., 2013; Henderson and Maguire, 2000; Lanie et al., 2004). Similar to our findings, in a study by Henderson and Maguire (2000) of Welsh undergraduate students, even those participants who went on to give fairly accurate, detailed explanations of genetic inheritance often began by stating that they had limited knowledge of genetics. This phenomenon may indicate that the lay public perceives genetics to be a complex field and feels a significant lack of understanding in this area despite many having a working knowledge sufficient for most situations. Lanie et al. (2004), recognize the potential benefit of a perceived lack of knowledge as an opportunity for education and suggest that individuals who do not recognize their misconceptions would likely be the most difficult to educate in a medical genetics encounter. Consequently, the uncertainty seen among participants in our study likely provides an opportunity to educate rather than a barrier to overcome.

The idea of genes lying dormant and being activated or triggered by some behavior or environmental exposure has been described previously. Some version of this concept has been described by participants from various populations, including Welsh undergraduate students, Australian women, and a racially-diverse sample of individuals living in low-income communities in Cleveland (Goldenberg et al., 2013; Henderson and Maguire, 2000; Thomson et al., 2014). Similarly, the general lack of genetic determinism or fatalism in the MGRM as demonstrated in participants' discussion of behaviors that can modify genetic predisposition has also been seen in other populations in the US (Bates et al., 2003; Goldenberg et al., 2013; Sanders et al., 2007). Nevertheless, the lack of fatalism seen in this population is significant because fatalistic health beliefs have been described previously among Latinos (Jun and Oh, 2013; Kinney et al., 2010). Potentially, the belief that genes need to be activated to cause illness mitigates a possible tendency towards genetic fatalism. However, one study of Latinas in New York city found less evidence of fatalism among the younger generation, indicating that there may be a shift away from this cultural belief among US Latinos (Sussner et al., 2015).

One aspect that did stand out among this population was the frequency of discussion of diabetes. Although diabetes has been mentioned in other studies of lay beliefs about genetics (Emslie et al., 2003), it seemed especially salient in this group. To some extent, this is not surprising given that Latinos have higher rates of type 2 diabetes (Caballero, 2011). Nevertheless, the salience of diabetes as a hereditary illness may indicate that diabetes could be a starting point for discussing genetic predispositions and behaviors to modify disease risk.

4.1. Limitations

Despite this study's strength in exploring an increasingly relevant topic with an understudied population, the study does have important limitations. First, this study was done in a specific demographic subset of the diverse Latino population, so the findings do not apply directly to all Latinos. Furthermore, the sample in this study tended to be more highly educated than would be expected of the foreign-born Latino population in the United States. A full 50% of participants in this study had a bachelor's degree or higher, while nationally only 12% of this demographic holds a bachelor's degree or higher (Ryan and Bauman, 2016). Even though the sample did include participants with less education, the overall themes identified may be less relevant to Latina

immigrants with lower levels of education. Finally, since this population was recruited almost entirely through the NIH research networks, it is possible that these participants are more biomedically oriented than other Latina immigrants.

Additionally, the organization of the interview may have primed participants to think in a certain way when discussing their models of genetics. Since the interview first addressed causal beliefs of breast and colon cancer, participants were likely in this mindset when the discussion turned to genetics, even though the researcher explained that the goal was to think about genetics in general. This may have contributed to participants' tendency to discuss common complex or multifactorial diseases in regard to genetics. As a result, our findings may not represent the full scope of these participants' beliefs of disease inheritance. However, the fact that non-dominant conceptualizations of genetics were identified that did not focus on common complex diseases indicates that any influence of priming was not so strong as to overshadow all participants' deep-rooted beliefs about genetics.

A final important limitation relates to saturation. During data collection and initial analysis, the focus was on the main conceptual model described (MGRM), and saturation of themes in this model was met. However, the two minor models described here were identified during further analysis once data collection was complete. There were fewer participants that described either of the minor models. Therefore, we cannot say that saturation was necessarily met in regard to these two models. It is possible that there are other important aspects of the EGDM and the PGRM that did not arise in our interviews, and we cannot rule out the possibility that there may be additional minor models of disease inheritance held by other members of this population.

4.2. Practice implications and future research

In discussing genetics, healthcare providers should be aware of the existence of lay genetic models in the public in general. Despite the limitations of our study, healthcare providers should know that at least some Latina immigrants hold genetic beliefs that are more similar to the general non-Hispanic white population than they are different. Providers do not need to assume that there are conflicting cultural beliefs about inheritance or lower genetic awareness in this population than would be warranted for a patient from any other population. This is especially important in the context of Browner et al. (2003) finding of "excess of cultural sensitivity" in genetic counseling sessions with Latino clients, which may impede understanding and trust on the part of the patient. Furthermore, healthcare professionals should recognize that most people, regardless of education, have some uncertainty regarding their own understanding of genetics and use that uncertainty as an opportunity to fill in important gaps in knowledge. Despite this insecurity in their own understanding, many participants did have correct ideas in addition to misconceptions. Our study identified three diverse models of the role of genetics in health among Latina immigrant women, and there are likely others, especially among individuals more representative of this population. Consequently, eliciting a patient's own beliefs about disease inheritance prior to providing education will allow the healthcare professional to identify important areas of education and ways to relate this new information to the patient's existing model.

The pervasive idea of the dominant model we identified was that genes interact with the environment or behavior, which should be helpful for providers discussing multifactorial conditions with patients who may have a familial risk of illnesses such as cancer, cardiovascular disease, Alzheimer's, diabetes, or obesity. Providers ought to capitalize on these opportunities to reinforce positive health behaviors such as diet and lifestyle changes to improve health outcomes and reduce disparities. On the other hand, the general lack of discussion of Mendelian genetic conditions may mean that some Latinas will struggle more to understand these types of inheritance and their health implications. A small group of participants in this study focused more on the power of the mind or the role of emotions in disease. These individuals may present a greater challenge to healthcare providers who seek to make recommendations based on Western medicine that must be made to fit within patients' existing belief systems.

Our findings also highlight the need for future research in this area. As mentioned in the introduction, our study was only of a subset of the Latino population. Studies of lay beliefs of genetics including Latino men, US-born Latinos, and Latina immigrants whose education level is more representative of the national Latino immigrant population could shed light on ways in which our findings do or do not represent models held by this broader population. As mentioned above, one of the limitations of this study was that we did not reach saturation in the descriptions of the two minor models of disease inheritance. Consequently, an area of future research could be to further describe these models and conduct additional studies to identify whether other minor conceptualizations of disease inheritance exist in this population. Finally, a research design formally comparing Latina immigrant mental models to an expert model could identify specific areas of difference for providers to be aware of in working with these patients.

5. Conclusion

This study found that at least some Latina immigrant women have lay beliefs about disease inheritance that are similar to those identified in studies of other Western populations. It extends the literature by beginning work in the area of conceptualizations of disease inheritance in the Latino population. Our findings present data for healthcare providers regarding these health beliefs which can inform their approach to educating patients. Our data suggest that educational approaches to Latina patients do not need to assume culturally informed beliefs about disease inheritance. This is not to say that they do not require the use of culturally-sensitive language, images, and means of presenting information. Finally, this extension of the existing literature highlights additional areas in which further research could extend our understanding and improve our patient-provider interactions. As the largest minority group in the United States and a rapidly growing sector of the population, we cannot ignore the beliefs of Latino patients and their impact on health outcomes. As shown by this work, we cannot assume that these beliefs are either so similar to nor so different from those providing them care but rather, in the true spirit of cultural competence and humility, must keep an open mind and seek to understand each patient as an individual to provide the highest quality of care.

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