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Mental models about heredity among immigrant Latinx adults with limited education from Mexico and Central America

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Abstract

An understanding of genetics is becoming increasingly relevant to receiving medical care. It is important for health care providers and educators, including genetic counselors, to understand patients' perceptions about trait transmission and their interpretation of terms used in biomedicine. Knowledge about the patient perspective about trait transmission is important when health care providers are not fluent in the patient's language. Sixty Latinx immigrant adults (30 men and 30 women) who were born in Mexico or Central America (MCA) and living in North Carolina were interviewed about their heredity beliefs. By design, most participants had limited education. Eight percent had a least a high school education; 45% had less than a seventh grade education. Semi-structured, in-depth interviews were conducted to examine how participants think and discuss trait transmission. The translated transcripts were systematically analyzed using a case-based approach, supplemented by theme-based coding. Five lay mental models of heredity were identified that varied in terms of involvement of genes. Four of the five heredity mental models encompass genes; four out of five mental models do not link DNA to heredity. The centrality of blood, whether used metaphorically or literally, varies widely across the models. One model references God and depicts that heredity involves blood and/or genes, but not DNA. The mental models of heredity for most adult immigrants with limited education do not include DNA. Trait transmission by blood appears to have a more prominent role in lay mental models held by Mexicans than Central Americans. Increased patient knowledge about genetics can facilitate shared decision-making as genetics becomes increasingly relevant to medical care. Efforts to educate people can be most effective when we first understand the layperson's conceptions or mental models. Health care providers and educators should be aware that MCA adults with limited formal education hold diverse mental models about heredity.

KEYWORDS

genetic counseling, genetics, genomic literacy, health communication, Hispanic, Latino

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1 | INTRODUCTION

People try to make sense of their own experiences and those of people around them (Davison et al., 1992; Kleinman, 1980), whether it be trying to understand why one person develops cancer while another does not, or how a child can have blue eyes when her parents have brown eyes. Lay understandings are based upon people's experiences and observations, and may integrate biomedical explanations. In the context of trait transmission, people may develop mental models to understand how traits are transmitted (Allen et al., 2019: Johnson-Laird, 2010), and they may integrate genomic knowledge into their models to greater or lesser degrees. As an understanding of genetics becomes increasingly relevant to medical care, it may be particularly important for health care providers and educators to understand patients' perceptions about trait transmission and their interpretation of biomedical terms. This will be especially valuable when communicating with immigrants who have had very little formal education, often substantially less than is mandated in the United States (US). This analysis will therefore identify mental models about trait transmission held by a specific subpopulation of Latinx immigrant adults.

The perceptions of many adults living in the US about specifics regarding trait transmission are often a mix of terms or concepts used by biologists, geneticists, and lay terms or explanations. Lay adults may use some terms recognized by geneticists, but their use of terms and concepts may differ (Chapman et al., 2019; Hurle et al., 2013). Education influences the use of terms and concepts. However, research that examines genetic knowledge among community members often contains moderately to highly educated participants, thereby obscuring views held by less educated individuals. For example, 65% of the NC sample in Haga and colleagues' (2013) study had a bachelor's degree or higher. Among Christianson and colleagues (2010) NC sample, 47% and 95% had a bachelor's degree or a high school degree or higher, respectively. Only 24% of a sample of Mexican-born adults living in NC had at least a high school education (Mora et al., 2021). Within each of the studies, increased levels of educational attainment were associated with a greater concordance between participant and geneticist perceptions related to trait transmission (Christianson et al., 2010; Haga et al., 2013; Mora et al., 2021).

Much of the research that has examined perceptions about genetics among Latinx immigrants or migrants with limited education comes from studies that focus on knowledge related to specific diseases (Griffiths and Kuppermann, 2008; Kinney et al., 2010). Latinx community members and leaders in Utah, most of whom were born in Central or South America, provided feedback about educational materials regarding genetic testing for the *BRCA* mutations associated with increased risk of breast and ovarian cancer (Kinney et al., 2010).

What is known about this topic

Adult immigrants from Mexico and Central America (MCA) have varying levels of knowledge about how traits are transmitted between generations.

What this paper adds to the topic

Five mental models represent perceptions about trait transmission held by adult immigrants from MCA with limited education. Mental models of heredity for most of these MCA adult immigrants do not include DNA and most had only a vague concept of genes; trait transmission by blood appears to have a more prominent role in lay mental models held by Mexican than Central American immigrant adults. Knowledge about beliefs about heredity held by this population may improve communication about trait transmission.

They recommended that definitions be provided for terms such as "gene" and "mutation," suggesting that terms' meanings were unclear. Pregnant women living in California's Central Valley, most of whom were born in Mexico, were interviewed about their knowledge about prenatal screening for alpha-fetoprotein and diagnostic testing for chromosomal disorders. Few were familiar with the terms "chromosomes" or "genes." Many spoke about blood in the context of trait transmission, demonstrating an alternative understanding of heredity (Griffiths & Kuppermann, 2008). A qualitative study examined beliefs about trait transmission, not limiting the focus to trait transmission in the context of disease risk, among adults born in MCA, only 37.5% of whom had completed high school (Sandberg et al., 2017). Although most participants were aware that genes were involved in heredity, they had limited knowledge about how genes function. Participants also used "blood talk" to discuss heredity. Some participants appeared to refer to blood metaphorically to discuss trait transmission; others had a more literal interpretation (Sandberg et al., 2017). A study of Mexican-origin adults found that the two true/false questions that received the greatest percentage of correct responses were "Healthy parents can have a child with a hereditary disease" (true) and "Genes are made up of DNA" (true), at 74.0% and 68.5% respectively (Mora et al., 2021). They were also aware of limits of their knowledge; almost half of participants (47.5%) reported they were unsure whether a gene is a part of a chromosome.

Researchers who examine diverse cultural understandings of health and illness have placed people's interpretation of their own and ILEY-Genetic Counselors

others' experiences at the center of their work. Kleinman, for example, explored the explanatory models of people from different cultures about illness (Yang & Kleinman, 2008). He recognized that illness is not just an individual experience; it is embedded within a specific culture that understands the illness in ways that are meaningful for the individuals experiencing the illness, their families, and society. Leventhal and colleagues focus on people's common sense models that explain illness and disease which enables them to identify and evaluate coping responses (Baumann & Leventhal, 1985; Leventhal et al., 1992). These commonsense models of diseases are based on what individuals experience during acute illness episodes. Most people assign four attributes to their physical problems: identity (label and symptoms), cause, consequences, and duration of illness development, and recuperation. Similarly, in the context of risk perception, Davison refers to "lay epidemiology" (Davison et al., 1992). People observe cases of illness and death among people in their social networks and "in the public arena." Their assessment of those cases, including their specific contexts, may reinforce or challenge lay or scientific explanations.

The term "mental models" is also used to represent lay explanations. Drawing upon Johnson-Laird (2010), Allen and colleagues (2019) define a mental model as "an explanation or representation of an individual's thoughts about a topic and resulting consequences" (p. 85). Some researchers have focused on mental models related to specific diseases or symptoms, such as diabetes or mental illness (Daack-Hirsch et al., 2018; Schofield et al., 2019). Other researchers have examined mental models related to disease inheritance more generally (Fiallos et al., 2019; Henderson & Maguire, 2000). Condit has explored how people understand genetics (Condit, 2010, 2019; Condit et al., 2009). She notes that the lay public understands genetics in the context of heredity. Although they may be aware of academic research explanations, individual's understandings of heredity are also affected by experiences they have had with specific conditions (Condit, 2019).

Henderson and Maguire (2000) identified three mental models of disease inheritance based on data collected from a sample of 72 first year Welsh undergraduate students (see Table S1). Those espousing the Constitutional Model were aware that genetic material is inherited, but were unable to provide specific knowledge about location or function of genes. The Mendelian Model represents awareness of genotypes and phenotypes, that genetic predispositions and specific genes can be inherited, and that genes may be dominant, recessive, or related to sex-linked disorders. The Molecular Model recognizes that genes are made of DNA, located in cells, and recognizes genes' functional importance. This model posits that both genes and environment influence whether a disease manifests itself (Henderson & Maguire, 2000).

A more recent study identified three mental models held by Spanish-speaking Latina immigrants about disease inheritance (Fiallos et al., 2019) (Table S1). Thirteen of the 20 Latina immigrants interviewed had at least some college, six had a high school diploma, and one had less than a high school diploma. Most participants described genetics and disease in a manner consistent with the Modifiable Genetic Risk Model (MGRM), and expressed that genetics is an integral part of an individual, underlies all aspects of that individual, and that an individual's disease risk can be modified by behaviors; many diseases are not influenced by genes alone. Explanations about how genes function to influence disease development varied. The Extraordinary Genetic Disease Model represents an understanding that genetic diseases are distinct from other health concerns. Those holding this model focused on rare conditions caused by genetic disorders, and addressed the role that genes may have in more common diseases, such as diabetes, that are influenced by genes, environmental exposures, and behaviors. Finally, the Peripheral Genetic Risk Model posits that genetics do not play a central role in disease causation. Non-genetic explanations were evoked to understand disease (Fiallos et al., 2019).

Identifying and describing a populations' mental models is valuable in developing effective genetic educational interventions (Allen et al., 2019; Condit, 2010, 2019). Mental models bring focus to the identification of explanatory narratives and the perceived causal logic that flows from the model. Comparison of lay models to expert models can then enable the educational team to develop strategies to build upon the lay models and address differences (Allen et al., 2019; Morgan, 2002).

The current analysis expands on prior studies that examined mental models about trait transmission with a sample of men and women adult immigrants from MCA, most of whom have less than a high school education, many with less than a middle school education. Development of these lay mental models will facilitate understanding of the different ways that this vulnerable population thinks and talks about trait transmission so that effective strategies to convey genomic concepts can be developed. The primary aim of this study was to identify the mental models held by MCA adult Latinx immigrants with limited to moderate education about trait transmission, particularly in the context of central genomic concepts. A secondary aim was to analyze whether mental models varied by gender, education, or region of birth Mexico or Central America.

2 | METHODS

This study was part of a larger project to develop and evaluate a community model of informal genomic education that is culturally and educationally appropriate for low-literacy Latinx adults born in MCA. It was approved by the Wake Forest School of Medicine Institutional Review Board.

2.1 | Participants

This study aimed to recruit a sample of Latinx MCA immigrant adults living in NC, most of whom had less than a high school degree or equivalent. The bilingual study project manager (GT) recruited participants at diverse sites, such as community care clinics, stores, and churches. Community partners also facilitated recruitment. The project manager explained the study, including FIGURE 1 Biological Model and Lay Models that represent perceptions about trait transmission among Latinx MCA immigrant adults with limited education



what participation would involve, that involvement was voluntary, and that the participant would receive \$40 after the interview. Inclusion criteria were (1) age 18 or older, (2) born in Mexico or Central America, (3) reside in NC, and (4) speak Spanish. Individuals who had a child 13 years or younger were excluded to prevent recruiting potential participants for a later component of the larger study. Half of the 60 participants were to be men and half were to be women; no more than 10% of participants were to have a high school education, and at least 33% were to have the equivalent of a sixth grade education or less.

2.2 | Data collection

Data were collected from February to August 2017 by the project manager (GT), an experienced, trained, bilingual interviewer. Interviews took place in the participant's home or at other private locations of his or her choice. The interviewer explained the project and obtained signed informed consent in Spanish prior to the interview. The audio recorded semi-structured, in-depth interviews lasted an average of 60 min, ranging from 40 to 80 min.

An interview guide was developed to ensure that the same topics were covered in all interviews and to elicit rich, detailed responses about how participants who may have little to no knowledge about genetics think and talk about trait transmission (see online Appendix S1). The first part of the interview asked the participant general questions about trait transmission, such as why some children may have hair and eye color that resembles one parent or the other. Specific questions about genes, DNA, and their functions were asked later. Due to the predominant role of blood in the context of trait transmission in a prior study of MCA immigrant beliefs (Sandberg et al., 2017), participants were asked whether or how blood was involved in heredity. Relationships between genes, DNA, and blood were also probed. Saturation was achieved, i.e., no novel explanations were forthcoming (Morse, 2015).

2.3 | Data analysis

Interviews were transcribed and translated from Spanish to English. Transcripts were checked against the audio recordings by the bilingual project manager. A case summary, which was developed to describe participants' mental models about heredity, was prepared for each transcript for the case-based analysis by one of three team members (JCS, TDH, DM). Each transcript was carefully reviewed to determine how participants perceived inheritance of traits and the different factors involved (or not involved) in heredity. Particular attention was given to the perceived involvement of genes. DNA. and blood in heredity. A second team member reviewed the case summary (GT). All team members read the case summaries; general similarities and differences among the cases described by the summaries were discussed. Diverse mental models were identified. Texts attached to codes, such as "genes," "DNA," and "blood" were extracted from the transcripts when direct quotations or clarification were needed.

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A codebook was constructed to list and describe the codes that represented key concepts. Basic codes, such as genes, DNA, and blood were identified a priori. Code definitions were refined as more interviews were conducted (Creswell & Plano Clark, 2011). Codes or "tags" were electronically attached to segments of the transcripts that corresponded to the. Definitions were iteratively modified with discussion among team members. Each transcript was coded by at least two team members (GT and JCS, TDH, and DM) (Luborsky, 1994). The same person who created the case summary conducted the second coding for the transcript.

ATLAS.ti v7 (Scientific Software Development GMBH, Berlin) software was used as a data management tool and to facilitate analysis. After all transcripts were assigned a mental model category, a table was created to evaluate the distribution of gender, educational attainment, and geographic region for each mental models category. Quotations in this manuscript are identified by the participant identification number, gender (M-man, W-woman), education (EI – 6th

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grade or less, MS – 7th–9th grade, HS – 10th grade – completion of high school/GED, 1C – 1 year of college), and region (Mex - Mexico, CA - Central America).

Images using Venn Diagrams were created to represent the biological heredity ("expert") mental model and five lay heredity mental models. While we recognize that Venn diagrams have limitations in representing complex concepts that involve genes, DNA, etc., we used them to help readers visualize the relationships among different concepts in the context of heredity. The size of the circles or ovals represents the prominence of each concept within each mental model. The overlap, or lack thereof, of the shapes represents the overlap of concepts in the mental models. For instance, as depicted in the biological model used in current western medicine, "heredity" is an all-encompassing term that includes all of the other terms represented in the model (Figure 1, Biological Model). Heredity is determined by the inheritance of DNA, and "genes" are made up of "DNA." Genes are only a subset of the DNA circle, since all DNA does not encode for genes. Genes are responsible for both "Mendelian" genetics, i.e., diseases or traits determined by mutations of single genes, and "Multifactorial" genetics, so both of these concepts are fully included within the "Genes" circle. The gametes ("Sperm & Egg") are clearly important in heredity (and thus the overlap), but are also unique.

3 | RESULTS

Sixty participants completed the in-depth interviews (Table 1). Fourteen, twenty-eight, and eight participants were <30, 31–50, and >50 years of age, respectively. By design, half of the sample were men and half were women. Most participants had limited education; 27 (45.0%) participants had a 6th grade education or less, 15 (25.0%) had a 7th–9th grade education, 14 (23.3%) had completed 10th–11th grade, only four (6.7%) had completed high school or an equivalency test, e.g., G.E.D, and one had completed one year of college. Thirty-nine participants were born in Mexico, and 21 were born in a Central American country.

Five mental models were identified (Figure 1 and Table S1). The Genes & DNA Model is most similar to the Biological Model, and the Genes as Trait Carriers, Genes & Blood, and the Blood Centrality Models are increasingly dissimilar to that model. The God-talk Model includes reference to God as an explanatory mechanism. Twelve, thirteen, fifteen, eleven, and nine participants' explanatory frameworks were represented by the Genes & DNA, Genes as Trait Carriers, Genes & Blood, Blood Centrality, and God-talk Models, respectively.

3.1 | Genes & DNA Model

The Genes & DNA Model (N = 12) represents an understanding that traits are inherited both through genes and DNA, although that relationship between the two may or may not be clear (Figure 1).

Furthermore, genes are the predominant explanation for trait transmission. Participants whose views are represented by this model may have some familiarity with Mendelian genetics, and they may report that sperm and eggs are relevant to heredity. Finally, blood may be mentioned in the context of heredity, but it does not have a central role.

Knowledge that genes and DNA are somehow related to heredity is central to this model. Some participants may have a solid understanding about the relationship between genes and DNA as reflected in the following statements: "Genes are basically inside the DNA.... DNA is a combination of all genes that one person has, maybe, and when the child is born, the DNA mixes, from the father and the mother" (4: M, MS, Mex). To explain why he looks like his dad, another man indicated that he came from sperm from his dad. The sperm contains "genes, and that little chain we had talked about. Part of it comes from my dad's DNA and maybe that is why I look like him" (32: M, El, CA). Others were aware that DNA and genes are related to each other, but not sure how. For example, one man reported that genes have something to do with trait inheritance and that DNA and genes are connected in some way, although he was unsure how. He described DNA as what defines a person (50: M, MS, Mex). The level of detailed knowledge about DNA also varied. As one participant noted, "DNA... contains the real information and I guess the genes are the transmitters.... You can't unlink DNA from genes. They are related" (15: W, HS, CA). Another woman noted that traits are passed on through genes, through cells in the body; she perceived that DNA, genes, and cells are the same thing.

Participants assigned to this mental model may have had some familiarity with concepts that underlie Mendelian genetics. A woman who had completed high school provided the most detailed description.

> I remember when we were in science class. It was my favorite class, so we would draw the chart with all the genes and Aa, Bb, Cc. And you would write the genes and some were the same, but there was always one that was different. So, I always think, 'Oh, this one has this color, but this one doesn't look anything like that, because he got the gene that doesn't look like the other ones.' ... But the genes always have something to do with it and they also skip generations, because sometimes parents have colored [i.e., non-black] eyes, but I don't and neither do my siblings, but my son does, so it totally skipped me and the other one got green eyes like my mother's side

> > (3: W, HS, CA).

Other individuals' ideas may be consistent with some concepts associated with Mendelian or multifactorial genetics; but the wording they use did not enable the research team to determine this. For example, this quotation may or may not represent a colloquial description of Mendelian genetics: "Sometimes the dad's DNA is stronger than the mom's [DNA]. So even though they're providing

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TABLE 1 Sample characteristics and frequency of Lay Mental Models by characteristics

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the same amount, but if the dad's is clearly stronger, then the child will look more like the dad" (45: M, HS, Mex). This could be construed as an explanation for a dominantly inherited trait, although that is unclear. Other participants provide responses that appear to be consistent with codominant genetics. A woman indicated that men "also transmit their genetics in the semen and when it mixes with mine, there's a result. I imagine it's like mixing colors. Yellow and blue gives you green" (15: W, HS, CA). However, she had difficulty explaining why siblings may have different shades of green eyes, and mentioned that the parent with the stronger personality may be more likely to have his or her traits transmitted to his or her children.

Several participants referred to sperm, eggs, or semen while explaining trait transmission, as evident from participants 32 and 15's quotations above. Another woman supposed that genes are passed through the ovum (1: W, HS, CA); and a man used the terms genes, chromosomes, and DNA interchangeably when referring to the conception process (45: M, HS, Mex).

Reference to blood in the context of heredity was fairly limited. Some participants clearly stated that blood is not passed through generations. Several participants reported that genes and/or DNA are found in the blood. As one participant indicated, "Genes are the cells in the body. I imagine that we have all of that in the blood" (12: MS, 43, Mex). Another participant used the terms genes and blood interchangeably (50: M, MS, Mex). These latter references suggest that "blood talk" may at times be a metaphorical way to talk about trait transmission.

3.2 | Genes as Trait Carriers Model

The Genes at Trait Carrier Model (N = 13) represents an understanding of heredity in which the role of genes in trait transmission is central (Figure 1). DNA is neither perceived to be related to genes nor involved in heredity. Blood may be referred to in the context of trait transmission. Sperm or eggs may be recognized as being involved with heredity and associated with genes.

Genes are at the center of this model of heredity, although conceptually their role is generally vague. Genes are still described as the carriers of traits.

> [Genes are] in the blood, [and] in your mind. Like I said, there are different types of ways to decipher genes. [They] can be inherited, like perhaps [they] can be in diseases or in decisions that you make where you question yourself, why did I make this decision? Because that decision comes from the genes. That's [why] you make those decisions

> > (13: M, HS, Mex).

Other participants had vague conceptions about genes. For example, one participant noted that people say: "'Look, they look more like you or more like their mom.' Well, I guess it's because they get more genes from me or from their mom, I don't know. I think that's why,

right?" (53: M, MS, Mex). Some participants described trait expression from one parent over the other due to dominant or stronger genes.

One is more dominant than the other.... I imagine that it depends on the quality of genes. There are some genes that are stronger, more predominant than others. And when there's an embryo, well, the more dominant gene, I assume.... It's the one that develops more – I think – perhaps I'm mistaken

(9: W, E1, CA).

Participants whose ideas were consistent with this model either did not know what DNA was or did not discuss it in the context of trait transmission. Among those who had heard of DNA, it was primarily discussed in the context of identifying a person or DNA testing, particularly paternity testing.

> Well, DNA identifies, and genes are like an inheritance – like something that is passed down through your family. Like when they say, "Look how tall you are, you look like your uncle." "You look like your grandfather." Or when they say, "Look what nice eyes you have. Those are from my grandfather." Those are genes. DNA is [used for] identification.... DNA identifies where you come from

> > (58: M, 1C, CA).

When another participant was asked if she had ever heard of DNA, she stated "DNA, yes. It's a test that they do to know whether a child belongs to your partner" (41: W, El, CA). She indicated that blood, saliva, or hair could be used for the DNA test. However, she lacked understanding of the relationship between genes and DNA, and specifically that genes are made up of DNA.

Blood may be mentioned in relationship to heredity, bloodlines, or genes among participants who hold this mental model. Some participants indicated that genes or DNA are in the blood. As one participant explained, "[blood] is the matrix of genes. The most important thing, aside from the fact that it's what makes the body function, that's where we have everything.... I assume that you can't see [genes]. They're dissolved. They're invisible, but then they develop. [Genes are] like oxygen" (9: W, EI, CA). Others indicate that blood is not involved in heredity. A few used genes and blood interchangeably. When asked why one child has lighter eyes than the other, a man stated, "It's through genes, through blood" (26: M, HS, Mex).

Most participants in this category did not bring up sperm or eggs during the interview. However, a few indicated that genes were transmitted from one generation to the next through sperm or eggs. One participant who had already talked about genes in the context of trait transmission was pressed by the interviewer a bit more. When trying to explain why his children look different from each other, he stated "It's different because it's not my same sperm or – or any of that. I mean, it has to be different. It can't be the same" (13: M, HS, Mex).

3.3 | Genes & Blood Model

Genes & Blood Model (N = 15) represents an understanding of heredity that involves both genes and blood, with blood having a greater role than it did in Genes as Trait Carriers (Figure 1). "Stronger" blood may influence trait transmission; blood plays a larger role in heredity than among previously discussed models. The concept of genes is often vague. The participants who hold this mental model may be aware of DNA in the context of DNA testing, but not perceive that it is involved in trait transmission. A minority of participants discussed sperm or eggs in the context of trait transmission. They were only discussed within the context of heredity, and are therefore encompassed within the heredity circle. Genes were understood to be involved in heredity, although the descriptions often lacked specificity. As one participant indicated, genes "make us look like our ancestors" (49: M, HS, Mex), but had difficulty providing specific information about what genes are. When referring to genes associated with traits that are not expressed, another participant indicated that genes "stay encapsulated, and get trapped in our body. At some point they expand...and they start to reproduce" (28: M, MS, CA).

The overlap between participant language about blood and genes is reflected in the following quotation. "I think it depends on who has the stronger blood between the two of us. That's where the gene is better reflected, I think, whether it's the mother or the father" (21: W, HS, Mex). Another participant mentioned that people sometimes say that the mother or father had "stronger blood" depending on which parent a child resembles. He indicated that there is a mix of blood, and the child resembles one parent or another depending on the strength of the blood. He was aware that traits can skip generations, but was unable to articulate how. Although he initially indicated that he does not know what genes are, he later stated that parents' traits are transmitted through genes in the blood (6: M, El, Mex). Another participant had very little understanding about how traits are passed from one generation to the next; his blood-related explanation appears to reflect his experiences with the health care system. When asked if heredity and characteristics have anything to do with blood, the participant responded:

> I think everything comes in the blood, right? I think everything we see, the tests and everything, they come from the blood. I think everything that is medical, the tests that they do, DNA, ..., I think it's what's most essential, but I don't know. I know everything comes from the blood, because they always ask for blood

> > (16: M, MS, CA).

The fact that genes are composed of DNA was not understood. DNA was not perceived to be involved in trait transmission. DNA was described as something that could be found in the blood or other parts of the body, like hair, that is used to identify a person or relationships between individuals. As one participant stated, "For me DNA is – for Adional Society of Secret Vice 1097 Genetic Secret Vice 1097 Counselors

example I have a son but they want to prove it's my son. Well if you have the same blood, it's your son" (35: W, MS, Mex). Another participant also noted the role of DNA in determining paternity. "DNA is when you both get a blood exam to test if it's your son or not, something like that. That's DNA." (16: M, MS, CA).

Although rare, one participant noted that traits are passed to a child either through "semen" and "ovum" or through blood when conception occurs; however, the mechanism is often unclear. A few mentioned that blood is directly passed to offspring, while others said that genes are in blood, but blood is not directly passed on. One participant mentioned that traits are carried by sperm, and that the mother's nourishment may affect the child's traits, such as skin tone (42: M, HS, Mex).

3.4 | Blood Centrality Model

Blood is the key to heredity in the Blood Centrality Model (N = 11). Traits are passed through the blood (Figure 1). The participants adhering to the model were rarely familiar with the term genes. Among the few who were familiar with the term, genes were perceived to be in the blood, but these participants had only extremely vague understanding, if any, that genes are associated with heredity. Although they may have been familiar with DNA in the context of paternity or identification of people, they rarely perceived a connection between DNA and trait transmission.

Participants explained that trait transmission occurs through blood, but they cannot explain how blood is passed down to offspring. Some participants referred to the strength of a parent's or grandparent's blood. "My son, they say he looks like his grandfather. I think my father-in-law has the stronger blood, right?" (44: W, EI, Mex). Some participants suggested that children may look like one or the other parent due to blood received from parents. Other participants expressed that children receive traits from both parents because blood combines or mixes. "I figure it's because [blood] combines and they get something from him and something from me, I mean, that's what I think. It's how it mixes – I think, it's – it's like they say, together but not – in this case it mixes" (20: W, EI, Mex).

The majority of the participants were unfamiliar with or had never heard the word gene. Those familiar with genes perceived them to be in blood, but could not relate them to trait transmission. For example, when asked why family members look like each other, one participant responded, "I imagine it's because of genetics" (117: W, El, Mex). When asked what "genetics" or "genes" are, she indicated, "I imagine the family characteristics, the blood," but was unable to provide any more information about what genes are.

The concept of DNA was not understood, and some participants had never heard the word. The few participants that could talk about DNA rarely related it to trait transmission. Those who had heard of DNA described it as something that dictates blood type, the name of a medical test, or something that can be found in the blood or other parts of the body that can be used to identify a person or relationships between individuals. For example, one woman had heard that -WILEY-Genetic

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DNA is used "to find out whether the child belongs to the father and the mother" (36: W, El, Mex). The rare case in which DNA was mentioned in the context of trait transmission, blood was also mentioned. A participant indicated that children look like their parent "because of blood.... [Blood] is like the DNA from the mom and the dad." She later stated, "I think that blood makes you turn out a certain way. For example, different blood is combined than what was previously combined. It's different" (19: W, El, Mex).

3.5 | God-talk Model

The key feature of the God-talk Model (N = 9) is that God is referred to in the context of trait transmission (Figure 1). Traits are passed down through blood or genes. DNA is not reported to be associated with trait transmission. Sperm or egg are mentioned infrequently by the people whose beliefs are represented by this model.

God is referenced when explaining why individuals have specific traits, particularly when an individual has difficulty explaining the presence of a trait or condition using other explanations. Participants' perceptions about the relationship between God and genes or DNA vary. One man who had not heard of the word gene and knew about DNA only in the context of testing was asked to explain why some children do not look like their parent. He responded: "Only God knows that answer" (14: M, El, Mex). Another participant who recognized that genes transmit traits had difficulty explaining why a child might not look like other family members in the context of genes. God may have an influence on traits that supersedes the impact of genes. "Or maybe [the child] doesn't look like anyone. It's not because he has a different father or anything; it's just that God does things too, aside from genetics" (2: W, El, Mex).

God appears to be invoked at times as an explanatory mechanism when participants were at a loss to explain children's traits. However, participants whose statements were consistent with other models also admitted to being unsure whether their responses were accurate or were unable to provide a response, noting that they did not know the answer. Lack of certainty about the mechanism through which trait transmission occurs is not limited to those who refer to God.

Another participant who was aware that genes relate to heredity, but had difficulty explaining what genes are or how they function, integrated the influence of God with the role of genes: "I think that when God created, God—he established genes in each person. That's my opinion.... We come from a creator, and he placed the genes in humans. And that's where we come from, as descendants. Because even the Bible talks about the first to the fourth generation would inherit" (8: W, MS, CA).

Participants who did not mention God also indicated that traits are passed down for multiple generations, usually four generations. This belief may be related to multiple selections from the Hebrew Scriptures. Exodus 10:5–6, for example, states that "You shall not bow down to them or worship them; for I, the Lord your God, am a jealous God, punishing the children for the sin of the parents to the third and fourth generation of those who hate me..." (New International Version). Many MCA immigrants who have been influenced by Christianity may perceive a link between such biblical texts that address the sin of a parent being passed down for three or four generations and trait transmission.

Only one participant mentioned sperm and eggs. She noted that family traits result from the union of the egg and sperm. At the same time she noted that after that union, it is "God's will whether that person lives or dies," and then reported that children look a particular way due to "God and genetics passed down from generations" (5: F, HS, CA).

3.6 | Frequency of models by personal characteristics

The percentage of participants represented by each of the five models were roughly similar; they ranged from 15.0% to 25.0% of the total sample (Table 1). Given that there are five models and a relatively small sample size, statistical analysis of the distribution of participant characteristics across the different models is inappropriate. However, some trends appear in the data. The youngest participants were overrepresented in the Genes & DNA Model and underrepresented in the Blood Centrality Model. Participants aged 31-49 were overrepresented in the Genes as Trait Carriers and Blood Centrality Models. Those aged fifty and older were overrepresented in the Genes & Blood Model and underrepresented in the Blood Centrality Model. Men appear to be overrepresented in the Genes & DNA, Genes as Trait Carriers, and Genes & Blood Models, but underrepresented in the Blood Centrality and the God-talk Models. Participants who completed at least tenth grade were overrepresented in the Genes & DNA Model and underrepresented in the Genes & Blood, Blood Centrality, and God-talk Models. Participants who had completed sixth grade or less were underrepresented in the Genes & DNA and Genes as Trait Carriers Models and overrepresented in the Blood Centrality Model. Participants born in Mexico were overrepresented among Genes & Blood and Blood Centrality Models, but were underrepresented in the God-talk Model. The Blood Centrality Model has the greatest lack of balance between people with different characteristics. Of those whose ideas were consistent with the Blood Centrality Model, most were ages 31-49, women, had completed <7 years of school, and were born in Mexico.

4 | DISCUSSION

There are five distinct lay mental models that represent ways that MCA immigrants living in NC speak about trait transmission. Four of the five mental models encompass genes; four out of five mental models do not link DNA to heredity. The centrality of blood, whether used metaphorically or literally, varies widely across the models. The Genes & DNA Model is most similar to the Biological Model. The role of genes is dominant in the Genes & Trait Carriers Model. Both blood and genes influence trait transmission in the Genes & Blood Model, with blood having a larger role in heredity than in the Genes & DNA and Genes as Trait Carriers Models. The role of blood in heredity is dominant in the Blood Centrality Model. Only one model references God; the God-talk Model depicts that heredity involves blood or genes, but not DNA.

These lay models are represented as being discrete. However, the model invoked by an individual at a particular moment is influenced by how much knowledge that individual has about the biological model of heredity, the specific context in which trait transmission is raised, and in the context of interviews, the questions asked (Condit, 2019). Individuals assigned to models that reference genes or DNA may on some occasions draw upon models that exclude one or both terms.

These lay models show that substantial numbers of Latinx adults with low to moderate education understand that genes are involved in trait transmission, although they may have vague understandings about what genes are. The models indicate that few understand that genes consist of DNA and that DNA is therefore relevant to trait transmission. The talk about DNA was often in the context of determining paternity or identifying a body.

Other researchers have noted that Latinx adults refer to blood in the context of trait transmission, including as a cause of birth defects (Griffiths & Kuppermann, 2008; Sandberg et al., 2017). However, reference to blood was less frequent among participants in this study than among MCA participants in Sandberg et al.'s (2017) study. In that study, some Latinas who spoke about trait transmission through the blood appeared to be speaking metaphorically, while others appeared to have a literal interpretation. This is consistent with this study.

The use of "God-talk," reference to God in explanations, while speaking about trait transmission, is not unique to this study. Fiallos and colleagues' (2019) study of 20 Latinx women provided an example of God-talk in the context of their discussion about participants' insecurity in their genetic knowledge. "Sometimes people say that they're curses [that cause alcoholism], but - and things like that, only God knows" (p. 5). In the context of discussing beliefs about birth defects, some women from a different study attributed them as being "God's will" (Griffiths & Kuppermann, 2008). As noted in Sandberg and colleagues' (2017) study, when provided, "God-based explanations were usually, but not always, given in addition to other explanations" (p. 175). References to God's will by Latinx adults do not necessarily imply rejection of other, more rational explanations or feeling that one has no influence on outcomes (Penchaszadeh, 2001). Furthermore, reference to God's will to explain a condition or illness is not unique to the Latinx population (Costanzo et al., 2005).

Using the lay models of disease inheritance identified by Henderson and Maguire (2000), few participants in this study share perceptions that correspond to the Mendelian Model (Table S1) or the Molecular Model. Some of the participants may have mental models that correspond to the Constitutional Model. Many of the participants' mental models in this study are not consistent with any of Henderson and Maguire's models. The approach taken in Fiallos et al.'s (2019) study on disease inheritance does not allow for a comparison with the current study.

Although a small sample size precludes a statistical analysis, a few trends appear to be present in the data. Participants with 10-13 years of school were overrepresented among those whose perceptions about heredity are represented by the Genes & DNA Model, which is most similar to the Biological Model. The association between increased education and genetic knowledge has been noted in many studies, including those that include Latinxs (Haga et al., 2013; Harding et al., 2017; Mora et al., 2021). Although Fiallos and colleagues (2019) did not find any association between mental models and educational attainment, only 5% of the participants in their study had less than a high school education compared to 92% in this study. Also, mental models in this study focused on heredity broadly, not disease inheritance, and, therefore, content of the mental models are not directly comparable.

Correspondence to mental models appears to vary by region. Participants born in Mexico were overrepresented among those whose beliefs corresponded to the Genes & Blood and Blood Centrality Models. This suggests that blood talk may have a more prominent role among Mexican than Central American immigrants' understanding of heredity. This is consistent with the experience of genetic counselors working with immigrants from the Mexican state of Oaxaca who spoke an indigenous language, but neither English nor Spanish (Shen et al., 2018). They resorted to talking about "good" and "bad" blood and "a bad mixing of blood" in their counseling sessions to try to convey genetic concepts. Their relative success with this approach suggests that for the small number of patients the geneticists worked with who were from Oaxaca, "blood talk" had its benefits. Although not all, or even most, participants with less than a seventh grade education held a mental model corresponding to Blood Centrality Model, all of the participants whose mental model corresponded to that model had less than a seventh grade education. Women were also overrepresented in that model. These findings serve as a reminder that "blood talk" may not be appropriate for all Mexican immigrants, and that "blood talk" may be less meaningful for Central American than Mexican immigrants.

4.1 | Applications

Health care workers and health educators, including genetic counselors, should be aware that MCA adults with limited formal education hold diverse mental models about heredity. Many may lack basic scientific knowledge, including familiarity with basic terms relevant to human biology and trait transmission; however, others have substantial understanding of such terms. It could be beneficial for the health care and health educators to provide a simple description of each scientific term without assuming any prior knowledge. To avoid confusion, minimize the use of the word "blood." If the word is necessary, be explicit about its meaning and mindful of possible MCA assumptions to avoid miscommunication. Finally, understand that knowledge gaps may be filled with cultural explanations or religions interpretations. At the same time, it is also important to be WILEY-Genetic Counselors

aware that religious interpretations do not exclude the possibility that MCA immigrants have some familiarity with concepts that are part of the biological model of heredity.

4.2 | Strengths and limitations

This study has several strengths. It examines the lay mental models of heredity held by a sample of MCA immigrant adults, including equal numbers of men and women. The sample includes large numbers of persons who do not have a high school education. It explores those mental models by demographic characteristics, including country or region of birth.

This study was limited to one state in the US, although the participants represented diverse regions of Mexico and multiple countries in Central America. Furthermore, the sample size of 60 was designed to focus on Latinx adults with limited education. Findings therefore are not transferable to moderately or highly educated Latinx adult immigrants. Finally, all participants had to be fluent in English or Spanish. Individuals who were only fluent in an indigenous language were therefore excluded.

5 | CONCLUSIONS

MCA adults, including those with limited education, hold diverse mental models about heredity. The role of blood in trait transmission varies substantially. A majority of models include genes in trait transmission; however, DNA is often perceived to be unconnected to genes or trait transmission. Finally, the findings suggest that mental models of trait transmission among this population may vary by country or region, gender, age, and education. A larger sample size would be required to provide more definitive findings.

Health educators and health care providers need to be attuned to the different lay models that Latinx adult immigrants from MCA may hold about trait transmission. It does not necessarily follow that familiarity of terms reflects an understanding of that term that is shared by geneticists. Furthermore, the use of "blood" to discuss trait transmission may vary by country or region, and may have different connotations among subgroups of the study population. Care is therefore required when asking questions or trying to convey information about genetics with Latinx adult immigrants from MCA.

AUTHOR CONTRIBUTIONS

Joanne C. Sandberg: Conceptualization, Methodology, Validation, Formal Analysis, Writing – Original Draft, Supervision; Grisel Trejo: Validation, Formal Analysis, Investigation, Data Curation, Writing – Review & Editing, Visualization; Timothy D. Howard – Conceptualization, Methodology, Validation, Formal Analysis, Writing – Review & Editing, Visualization; DaKysha Moore: Validation, Formal Analysis, Writing – Review & Editing; Thomas A. Arcury: Conceptualization, Methodology, Validation, Formal Analysis, Writing – Review & Editing; Sara A. Quandt: Conceptualization, Methodology, Validation, Formal Analysis, Writing – Review & Editing; Paul Kortenaar: Review & Editing; Edward Ip: Review & Editing. Authors Sandberg and Trejo confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Authors Sandberg, Trejo, Howard, Moore, Arcury, Quandt, Kortenaar, and Ip declare they have no conflicts of interest.

HUMAN STUDIES AND INFORMED CONSENT

Approval to conduct this human subjects research was obtained by the Wake Forest School of Medicine Institutional Review Board. All procedures followed were in accordance with institutional and federal ethical standards. Informed consent was obtained from all participants.

ANIMAL STUDIES

No non-human animal studies were performed by the authors for this paper.

DATA SHARING AND DATA ACCESSIBILITY

Data is available upon request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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