

Episode: *Ethics Talk: How the US Census Left Latinx Americans Behind*

Guests: Ruth Enid Zambrana, PhD, MSW; Fernando De Maio, PhD; Diana Derige, DrPH; and Diana Lemos PhD, MPH

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[mellow theme music]

TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff.

Did you know that prior to 1980 in the U.S., people of Latin and Hispanic ancestry were counted as White in the Census? While this might come as a surprise, this fact helps remind us that decisions about which data to collect are as socially, culturally, and politically situated as they are scientific. And these decisions are critical because collecting inaccurate data, or not collecting it at all, has the power to render health inequity invisible.

Most recent U.S. Census data suggest there's around 60 million people who identify as Hispanic or Latino in the United States. And when it comes to census data, who gets counted and how racial and ethnic identity is reported has lasting impact on democratic representation, public program funding, and voting district mapping. Researchers and policymakers who rely on these data, however, especially historical data, quickly run into a problem.

DR RUTH ENID ZAMBRANA: We have no longitudinal data on Latinos, because prior to 1980, U.S. demographic and health data collection identified all Latinos as White.

HOFF: That was Dr Ruth Enid Zambrana discussing this problem with us during a recent conversation about data collection and Latinx health equity research.

Given the history of racial and ethnic inequity and violence in the U.S., many people historically avoided publicly identifying as a member of a minority group. When the category Mexican American was first introduced to the U.S. Census in 1930, the League of the United Latin American Citizens and the Mexican government itself protested against the change, arguing that distinguishing Hispanic Americans from so-called White Americans would lead to discrimination. As the push for representation and visibility for historically marginalized communities became stronger in the U.S., however, accurate representation of racial and ethnic identity became, and continues to be, important in health equity research. And when it comes to Latinx populations in the U.S., one big hurdle is breaking down monolithic categories such as Latinx itself.

ZAMBRANA: We'll start out this conversation immediately observing the limitations of our data because of the clumping together of very, very different groups of people under the pan-ethnic umbrella of Latino.

HOFF: While national data is critical for large scale representation and public health goals, local data is also key to developing rich social and cultural understandings of specific Latinx individuals' and communities' health needs.

ZAMBRANA: Data by group and by place and by community was critically important because if we did not know what conditions these individuals lived, then we could not really contextualize their health problems. The data collected had to be embedded in an understanding of the place where people lived. And the other really important issue, which is now called “structural racism,” was how policies and practices impacted those communities. So, we needed data to understand what were the problems, what were the health problems, in this community? Which then we could have engaged in justice or equity, which is to work with the different resources in the areas to begin to address this. And national data is not representative of the health conditions of many of these communities.

HOFF: Up next, we'll talk with some colleagues from the American Medical Association Center for Health Equity. Drs Fernando De Maio, Diana Derige, and Diana Lemos worked with the Journal to develop this month's issue on Latinx health equity, and they joined us to discuss the purpose of this issue and the work the Center for Health Equity is currently doing to support Latinx health equity. Thank you all for joining me on the podcast today.

DR FERNANDO DE MAIO: Great to be here.

HOFF: So, I wanted to start out with this broad question of why it was important for the Center for Health Equity and the *Journal of Ethics* to team up to put out this issue on Latinx health equity.

DR DIANA DERIGE: Yeah, Tim, I'll start there.

HOFF: Mmhmm.

DERIGE: So, I'll lead us off in the conversation. I mean, we thought about this for a long time, as editors, of the importance of this. I think we all jumped at the idea to be part of it, and then we had a deep conversation about what that meant.

HOFF: Mmhmm.

DERIGE: And so, for me anyways, I think that thinking about the ancestry of the Latinx/Latino/Hispanic—depending on where you are and what you want to be called—we have ancestry from North, Central, South America, and the Caribbean. We recognize we have different immigration stories and status. We have different social-political relationships to the U.S. And so, there's a lot of complexities. And I think when we talk about equity, those complexities were used to kind of limit our story, to exclude us from conversations about health, or relegated to disease-focused things like diabetes or obesity. And I want to recognize that that omission, intentional or not intentional, adds to the structural barriers for both communities and peoples to tell their stories of who they are and what their life and world entails, but also how we advocate and organize to improve our health, to achieve health equity.

HOFF: Mmhmm.

DERIGE: So, part of this is about centering these voices, centering this conversation in a way that is inclusive and that helps us move towards recognizing that complexity shouldn't be an omission, right?

HOFF: Mmhmm.

DERIGE: That it is about this work, and it is the intersectionality that calls us to really understand health equity and figure out what to move on and to do.

HOFF: Wonderful. Thank you.

DERIGE: And I'll turn it over to my colleagues to see if they have anything.

HOFF: Sure.

DERIGE: I'm sure they have other thoughts.

DE MAIO: Yeah, I'm happy to jump in next. I think one thing that I would also acknowledge is as we look across the field of health equity, Latinx health equity, research, organizing, activism, there's a lot of activity and a lot of inspiration, right, a lot of great work that directly names and challenges the inequities in our society. And this is really important work, not just as an object of study, something that we want to learn about, but something that we can learn from, a source of insight for how systems of oppression work and ultimately how they could be changed for the better over time.

HOFF: Mmhmm. Diana, do you have anything to add to that?

DR DIANA LEMOS: I think the only thing that I would add is that I think with COVID, the issue and the impact that it's had on the Latinx community really has continued to highlight, at least for a lot of us who've been doing this work, the ongoing sort of segmentation or invisibility of a very diverse group. And I think that oftentimes, the Latinx health is relegated to immigration and forgetting that a large population of the Latinx community has been here. And so, when we try to sort of only focus on one area or one specific aspect of the community, we continue to erase or minimize some of these structural barriers, right?

And I think that by highlighting that and bringing that intentionality of really talking about the diversity of the Latinx community, really focusing on those structural factors, I think it allows for us to shift that narrative around what does it mean to be Latinx, and what does it mean to experience health inequities amidst all of these structural components? So, I think for us it was really, how do we tell that story and also do it in an authentic manner that many of us here identify as Latina or Latino or Latinx. And I think that that was also the additional motivational factor, at least for myself, in helping to be part of this issue specifically.

HOFF: One thing I wanted to ask about briefly was the use of the term "Latinx" itself as opposed to "Latino" or "Hispanic" or something like that, especially since it's been in the news in the days leading up to this recording as the League of United Latin American Citizens has said they will be dropping its use from official communications, although they made it clear that they're not making a statement against it for personal use or even for casual use within the organization. But since I imagine you've thought and talked a lot about this with each other in the conception of this issue, I wanted to get your thoughts on that.

DE MAIO: Yeah.

DERIGE: Yeah.

DE MAIO: We've been thinking a lot about language and terminology and the names that we attach to things. With the AAMC we just published a guide to the deep narratives, language, and concepts that has gained a lot of attention. And one of the elements that we explored in that document was what terms do we use for populations, like "Latinx, Latino, Hispanic?" We tried to listen to our colleagues, to our partners across the country, and our understanding is that there's no firm consensus yet. There is lots of debate around what terms to use in which contexts but no clear consensus on best practice for any one term that would fit the complexity of the communities, right? So, we listen, we approach this with humility, we recognize that there's no necessarily right or wrong answer. So, we approach this with flexibility.

HOFF: Mmhmm. Yeah. Thank you for clarifying that.

Let's turn to current AMA Center for Health Equity projects around Latinx health equity that you think our listeners should be aware of. This can be research, it can be community outreach projects, it can be publications, really just anything that you think folks who are interested in this issue might be interested to know that the Center for Health Equity is working on as well.

LEMOS: We've been prioritizing our work based off of the AMA's strategic plan to advance health equity and embed racial justice. And I think one of the key things about this work that we realize is that in order to really do this work well and to do and center projects around Latinx health equity, we're really thinking about examining our own role with it as a center and as part of the AMA. And so, in our strategic plan, we've undertaken the role of really examining our past harms affecting the Latinx community. So, I think taking a step back and really understanding about our history, not just the AMA, but within the U.S., and really having that nuanced understanding of the negative and structural barriers that the Latinx community has experienced and how that contributes to health outcomes that we're seeing right now, I think is an important first step.

I think the other part that I think is important to this work is related to our strategic approach around building alliances and sharing power. And how do we do that? Well, first, we recognize which organizations within our sphere are important. And organizations like the National Hispanic Medical Association and other marginalized physician organizations are those that we are prioritizing in terms of building relationships and forming and restoring trust, right? And so, with that, I mean, that takes time. It takes time for us to demonstrate that we're trustworthy, but it also takes time for us to build those relationships to ensure we're aligning.

HOFF: Mmhmm.

LEMOS: But we're doing a lot of that initial work of building relationships, identifying the correct partners.

And then I think the last point that I would probably highlight is just some of our responsiveness around COVID. And initially, we were fairly new when COVID, and I was probably three months into my role. And immediately our partners were reaching out and just sharing some of their concerns about what they were seeing within the Latinx community. So, we hosted a series of interviews talking to stakeholders and published some insights around the inequities that they were experiencing at the very onset and offered some opportunities and resources as a response to that. So, that's been something that we've worked on. And also starting to really think about the experiences of

physicians of minoritized and marginalized backgrounds. So, we also wanted to understand their experience during COVID. And so, we recently published another report that summarized the experiences of a diversity of physicians, including Latinx physicians.

So, I think for us right now, it's been more about understanding what's happening, building those authentic relationships, and sharing reports and insights to raise awareness about the issues that are affecting the Latinx community.

HOFF: Hmm. What is that process of building relationships with organizations who represent marginalized clinicians or other health professionals in general look like? As a few of you have noted, there's a history of harms done by the AMA to these communities. So, beyond just reaching out and saying like, "Hey, we'd like to coordinate on a report" or something like that, what is the process of relationship building and I guess power sharing look like?

DERIGE: So, our building alliances and sharing power is exactly what you said, right?

HOFF: Mmhmm.

DERIGE: Part of sharing power comes from the understanding that we first have to recognize our power, acknowledge it, and then wield it appropriately. And I say wield because people always want to shy away from it, you know?

HOFF: Mm.

DERIGE: They're like, "Oh, I don't have power." But we do, right? And there's different structures in place that do that. And so, for us, the Center, a lot of this is the organizing that Diana talks about. It's the trust building. It's showing up, right?

HOFF: Mmhmm.

DERIGE: AMA as a big institution, is used to saying, "Come meet me," right?

HOFF: Mm.

DERIGE: We need to show up and be in those places. Our presence, our participation as representatives of the Center for Health Equity at AMA is important to those conversations. It's also about humility and knowing when to step back in the conversations and be the host, possibly, right? When do we set the table and invite people to come in? Where are our opportunities to have those truer conversations? It has also been a test of our own balance and patience that you don't show up one day and be like, "Hey. So, let's all get together and fix this."

HOFF: Mmhmm.

DERIGE: And our organizations are like, "Well, we didn't make the problem. We didn't." And that is a fair assessment, right?

HOFF: Right.

DERIGE: And so, how do we show up and say, "We recognize there is a problem. Can you help us figure out what we can do to support you and support this work?" And so, it

has been this process of doing it. And so, we show up in different ways. I know that our colleagues are all the time at meetings and coalition conversations and contributing to different dialogues and also just waiting by the phone for when people want to have, like, “We think you can insert yourself in this way.” So, that would be my two cents on that.

HOFF: Mmhmm. Yeah, that’s very helpful. Thank you.

Part of responding to historical inequities requires comprehensive and accurate data that’s represented through individual stories like we’ve been talking about and that are featured in this issue, but also through larger aggregates. Can you talk a little bit about some challenges in how we currently gather health data among Latinx persons and populations? For example, in a conversation I had with another guest earlier this month, Dr Zambrana, she noted that prior to 1980, the categories of Latino and Hispanic weren’t even captured by national Census data, which obviously introduces a huge hurdle to any kind of longitudinal studies being done. So, can you speak to some of the other challenges and perhaps opportunities for accurate health data collection among Latinx populations?

DE MAIO: Yeah, you brought up a vitally important point, Tim. And I’ll share that I don’t think I ever filled out a survey or a Census that had the word “Latino” until I moved to the United States.

HOFF: Huh.

DE MAIO: I’ve lived here. I was born in Argentina. I’ve lived in Canada, the United Kingdom. And in all of those countries, we use a different classification system for race and ethnicity than we do here. And I think that’s really important, right, to recognize the social construction of the categories that are so, so vital in this country.

HOFF: Mmhmm.

DE MAIO: But really thinking broadly around this issue, I think there are two really big challenges that we have to face, and we’ve known about both challenges for a long time. They’re not new things. The first is the need for really granular data, data that lets us disaggregate between groups, recognizing the rich diversity that exists within a broad category such as Latinx. And the second is the need to collect data not just on individuals, but crucially, collect data to describe the history and the context of our lives, right? Here we’re talking about both the community level social determinants of health—for example, the level of income inequality in my community or in my city or my state—but even also further upstream drivers, including what Daniel Dawes calls the political determinants of health. To understand any population, the Latinx population as an example of it, we need to understand both the people in it and the structures that have shaped their lives, including the economic and political causes. So, we need to think about data in very holistic ways. It’s not just about health outcomes, important as they are, but we need to invest in data systems to really let us tell a story, the history, and the context of the root causes of inequities.

DERIGE: I think what I would add to that, with Fernando, I think those were all amazing points. I think there’s an opportunity as we’re evolving this conversation about Latinx, Latino, Hispanic, the collection of data, the disaggregation of it, the understanding of the nuances of it. There’s also an opportunity to bring communities along in this, right, to be part of this data collection, to have part of that storytelling. So, I always look at that opportunity of how can we do this together? How do we understand if we’re asking even

the right questions, right? Are we getting to, are we answering the question we really have, and how deeply is it laid? And data sovereignty: that this data, this information belongs to communities, right? And so, it should be the benefit of theirs, and they should have ownership of that. Those are really important things as we think about this because one of the questions we're often asked is, why is it important to do this research? And it's like, no, this is about people, right? Because they're about communities and real lives, and not just for the betterment of research or the knowledge as a broad thing. This is about, for me, anyway, this is about the organizing to an end of improving the health of millions of people and supporting that work.

LEMOS: I love all the points that have been brought up, and I think the compelling part for me is the importance of recognizing that the language continues to evolve. And even when we were preparing the work we were doing and looking at potential archives within the AMA and potential paths or harm or mention of the Latino community, or Hispanic or Latinx, we recognized that there's a dearth of data. And the reason is because that term did not exist, right? So, we had to become incredibly nuanced in terms of understanding who were the population, what were the population descriptions of that time? And within that time, I think everyone was called "Mexican" or it seemed like was given the title of "Mexican," right? And so, I think it's important because it limits our understanding as harmed, right? And it also continues to perpetuate some of these ongoing harms that are happening. And I think the data, if we don't get it right, if we don't get the descriptions right, if we don't allow community to come along on their journey, we're going to continue to do things that are very confusing.

So, for example, we still, many Latinos are said that they identify as white, right? And whether that's a choice or whether that's the only option that's available to them is still up for debate, right? And so, again, some folks can't identify Native American because the definition for Native American is very specific, right? So again, when we think about identities and we think about race and in the social construction of the way we're thinking about it in the U.S. and the lack of transferability to other parts across the globe, I think that it requires ongoing conversations with communities that are most impacted with that. And that presents challenges because language is going to continue to evolve. And we say that in the narrative guide. We know that that's a reality. And how do we try to make our language as inclusive as possible while allowing us to tell the stories of the people that are impacted, right? And I think that continues to remain a challenge for us.

HOFF: Mm, mmhmm. I wanted to ask briefly about a topic that seems kind of related to our ability to collect data and interpret it. And that is this popular conception of this Hispanic paradox. And for listeners who are unfamiliar, the Hispanic paradox claims that Hispanic or Latinx Americans tend to have health outcomes comparable to non-Hispanic white Americans despite lower socioeconomic status. So, what should our listeners know about whether, first of all, and how the "Hispanic paradox" affects how we approach and think about Latinx health equity? Is it just a matter of, as I think you've all spoken to, disaggregating our data such that we're not trying to talk about this monolithic "Latinx community" in a way that's not really helpful for the reality of the multitude of identities that's contained within that group?

DE MAIO: Yeah. Great, great question, Tim. And to be sure, there's been a lot of research, a lot of scholarship, a lot of debates around this paradox.

HOFF: Mmhmm.

DE MAIO: And as always, the details really matter, right? And the story becomes really complicated when we look at the specifics. So, if I could, I'll share one example from Chicago where between the period of 2012-2017, so just before COVID, Latinx life expectancy declined from 83.1 years to 80, right? So, there was a Latinx advantage in life expectancy relative to non-Hispanic whites, but that life expectancy advantage was lost in this very small time period, which raises all kinds of alarms in terms of epidemiology. There was nothing natural in that loss of that advantage, nor is there nothing natural or inevitable about the 8.8-year gap in life expectancy between non-Latinx Black and non-Latinx White populations in the City of Chicago. For many of us, we interpret these as patterns of what Paul Farmer and many others call structural violence, right, the political and social arrangements that literally harm populations.

We also see evidence in many studies, both here and across the United States, and they contend that the paradox is really less, is really about a health advantage for immigrants that is lost over time. There are lots of debates about why that might be the case. For a long time, people in health research in particular pointed to acculturation as the explanation. That is, as immigrants spend more time in the United States, we adopt less healthy habits. We eat more fast food and adopt sedentary lifestyles and so on and would therefore see a deterioration in our health status.

But one example, Professor Edna Viruell-Fuentes, the late professor of Latino Studies, someone who made a remarkable contribution to this area of work showed that acculturation really wasn't the underlying issue. She showed with qualitative work with Mexican immigrants how the process of othering worked in immigrant families. She showed how the social process of experiencing discrimination was not just an individual attribute, something that accumulates over time, but a social interaction grounded in the lived experience and our interaction in communities. So, her work and the work of many other Latinx scholars really adds nuance to the story that we might tell about the health of Latinx people and communities and this so-called health paradox.

HOFF: Great, thank you. Anything to add, Diana or Diana?

DERIGE: I mean, I think that Fernando covered much of that area. I think there's lots of conversation about this and especially about experiences of communities, the deterioration, right? And again, this is about the question that race is not the issue, right? Racism is.

HOFF: Mmhmm.

DERIGE: And we can look at that if we want to look at my experience in maternal and child health has shown us when we disaggregate, actually, our African-American Latinas have a much similar experience in their birth outcomes to African-Americans than they do their maybe lighter-skinned counterparts, right?

HOFF: Mmhmm.

DERIGE: And so, we have to look at what racism means and what that means to your body and to your health in general and over generations. And also, as we think about, Fernando mentioned the association with immigrant communities that we've also talked about, and there's things about the healthy immigrant theory as well and how that all plays out. There's also this protection factor that communities allow for each other. And as we see systems of oppression, as we see negative rhetoric expand, whether it be anti-immigrant or anti-Black, that has direct effect on communities' health, right? And it's not

just figuratively, it's literally. We have the data that shows when that appears, when it's hostile to live somewhere, health deteriorates, and we see that deterioration. So, I think that's important to recognize how that shows up because again, we often have this conversation where the identity of Latinx/Latino/Hispanic is an ethnicity, right? So, without recognizing that it has impacts, too, on our health and our phenotypes and how we show up and the narratives about who we are.

HOFF: Yeah. Yeah. Thank you. To wrap up, I'd like to turn to a topic that we normally close out the podcast with, and that is what health professions students and trainees should know about research into racial and ethnic health inequities, specifically related to access to health care, health outcomes, and overall health status. What should folks who are interested perhaps in engaging with the research in these areas know as they start their careers?

LEMOS: So, I just finished my first quarter teaching health equity to MPH and med students, so it's a little bit fresh off my mind. But I think the most important thing is that I think that the work is illustrating that our narrative and our approaches are changing, right? And I think that our focus on the biomedical model is expanding to really look at upstream, look at some of these underlying root causes, and that is really important. And it also takes a shift in your thinking, in your approach, and in really how you solve these problems. Because how you define them is ultimately the primary motivation of how you then address the problem, right?

And I think that we still have a lot of emphasis on intervening on the individual: you know, if somebody would just walk more, if someone would just eat less, or if someone would just eat more green vegetables, right?

HOFF: Mmhmm.

LEMOS: And we continue to ignore all of these other things that continue to persist and that could potentially bias our behaviors and our actions towards particular groups, especially, whether it's Latinx groups. And we saw a lot of these images coming up during COVID, where we continue to blame communities for their high rates of infection without looking at the policies, without looking at the lack of ability to work remotely or someone that's considered an essential worker but doesn't have protection, right? And so, I think that narrative shift is something really profound, and it's something that we have to do in practice every day. And it continues to really hold us to think differently about the problems and then also think differently about the solutions.

HOFF: Diana or Fernando, do you have any final thoughts that you'd like to wrap us up with?

DERIGE: I mean, I think it's one of these things that people try to talk about it being abstract. I think it's entering with humility, right?

HOFF: Mm.

DERIGE: I think that is really important. And the kind of the theory you're saying of knee to knee, and that means that you're, at any moment in time, knee to knee with your patient, client, or the people you're working with. And so, if you are that, you're there with them, right?

HOFF: Hmm.

DERIGE: You're not.... And that is something we're all learning and working for. But I would say that because it's the application, right? I can teach you a bunch of principles. We can make equity an administrative function, but it's not.

HOFF: Mm.

DERIGE: It is about how you show up and it is a long road and it is a wicked problem. We all have a role in it. So, standing up for that and being part of that solution.

DE MAIO: Yeah. And my standing advice to health professional students, really to any student, is what I did as well, is to learn the history, which most classes, most institutions won't push you towards. For me, one of my big developments was writing a book with David Ansell, John Mazzeo, in Raj Shah on the history of health equity work in Chicago, going back to 1901, the first map of excess child mortality that we have. Even before the community areas were officially designated, we had research that was showing unjust health outcomes. We had better maps by the 1920s and 1930s. And the challenge that I took on that I always try to share with my students is, what do we need to do differently, so we don't just produce better maps, right? So, we actually change what the maps look like, and we change the fundamental relationships in society. It would be unethical to just describe problems. It would be a waste of our talent and our resources. So, that's the challenge that we try to live up to, and I always try to inspire my students to take on.

And very lastly, just I want to thank you and the *AMA Journal of Ethics* for hosting us and helping us bring together this collection of papers. And we hope readers will take a close look at and think about and talk about. So, thank you. [mellow music returns]

HOFF: Yeah, as do we. I think it turned out to be a really fantastic issue. And thank you all so much for all of the work that you put into it and all the work that you continue to do at the Center for Health Equity and obviously well beyond the borders of the AMA in general. So, thank you again for being on the podcast today.

DE MAIO: Thank you.

DE MAIO: Thank you.

DERIGE: Thank you.

HOFF: That's our podcast for this month. Thanks to Dr Zambrana and my colleagues in the AMA Center for Health Equity for joining us. To read the full issue, visit our site, JournalofEthics.org. And for all of our latest news and updates, follow us [on Twitter](#) and [Facebook @JournalofEthics](#). We'll be back next month with an issue on unregulated supplements. Talk to you then.