

## Health Equity in US Latinx Communities

April 2022, Volume 24, Number 4: E249-341

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## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E251-253

### FROM THE EDITOR

#### Latinx Health Equity

Fernando De Maio, PhD, Diana N. Derige, DrPH, and Diana Lemos, PhD, MPH

Understanding the health of Latinx communities in the United States is a complex task. Doing this well requires moving beyond broad generalizations and recognizing that the Latinx community is not monolithic but actually very diverse.<sup>1</sup> Comprising over 61 million people<sup>2</sup> with a wide range of social, colonial, and political histories as well as lived experiences in the United States, the Latinx population defies any attempt at easy categorization.

Indeed, there are debates over what term should be used to describe this population; we use *Latinx* as an umbrella term intended to be a gender neutral and gender nonbinary inclusive term for all people who identify as Latinx, Latino/Latina, Latine, or Hispanic. Our use of *Latinx* also is intended to include those who choose to identify with their ethnic or national origin inclusive of the countries in Latin America and the Caribbean that were colonized by Spain or Portugal. The heterogeneity of this population is reflected in its diversity of political beliefs, cultural practices, languages, economic positions, and racial/ethnic identities—and perhaps most clearly in population health indicators, with some data showing a Latinx advantage (at least for some ethnic groups) and other data revealing the burden of racism, economic marginalization, and structural violence.<sup>3,4</sup>

In this issue of the *AMA Journal of Ethics*, we set out to bring together a new collection exploring Latinx health equity—not just as an object of study, something we want to know more about, but as a source of insight on how **systems of oppression** intersect to produce and reinforce health inequities<sup>5</sup> (ie, differences that are “avoidable, unnecessary, and unfair”<sup>6</sup>) across the United States. We wanted to broaden the discourse and expand the conversation beyond the topics typically associated with Latinx health equity—obesity or diabetes with an individual focus, immigration status, or acculturation narrowly defined. There are deeper, more complex issues that need to be elevated—notably, analyses of root cause, including racism and **colonialism**. So, our focus is not necessarily just on the Latinx patient or community per se, but on underlying systems that structure opportunity or oppression and advantage or disadvantage, how these systems manifest in health care and society, and—most importantly—how these **systems could be changed** for the better.

From the start of our process, we sought to build community among contributors, especially to include some contributors less experienced in academic publishing. The spirit of building an issue that was academically rigorous and authentic to contributors’

experiences required intentional effort to center voices that have been marginalized in many legacy institutions and in academic publishing practices. Our contributors persisted and remained dedicated to sharing their work in this issue. We thank them for taking this journey with us and for sharing their work. Each contributor to this collection offers a unique perspective, with different theoretical lenses applied in vastly different empirical circumstances. All these perspectives are needed to contribute to our understandings of structural and social drivers of health and hopefully will inspire efforts to shed light on the ethical failures of our current systems.

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**Citation**

*AMA J Ethics.* 2022;24(4):E251-253.

**DOI**

10.1001/amajethics.2022.251.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

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ISSN 2376-6980



## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E254-260

### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

#### Should Clinicians Be Activists?

Kristen N. Pallok, MD and David A. Ansell, MD, MPH

##### Abstract

Physicians are ethically bound to respond to undocumented, underinsured, and uninsured patients' health needs, even those demanding complex, expensive interventions, such as organ transplantation. A social medicine skill set of structural competency, allyship, accompaniment, and activism is required to best serve patients and communities and should be widely regarded as core competencies for all health professionals. This commentary on a case considers the nature and scope of the skill of activism, specifically.

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##### Case

JM (an actual patient) was 1 year old when he was brought to the United States from Mexico.<sup>1</sup> At 16, he developed end-stage renal disease, and JM's mother was an exact tissue match for a kidney transplant. Although undocumented, JM was insured through Medicaid under the Children's Health Insurance Program (CHIP). However, the Chicago children's hospital transplant program refused transplantation because it could not guarantee the lifelong antirejection medication regimen, as JM's CHIP coverage would expire in 2 years.

JM required dialysis 3 times weekly, a less effective treatment than, but a bridge to, kidney transplantation.<sup>2</sup> JM's mother sought assistance from an activist priest whose congregation comprised undocumented and uninsured residents, many of whom had organ failure. Like JM, they were denied access to transplant evaluations at Chicago transplant centers because they were uninsured.

While transplant ethics and law demand **equity in access** to transplantation based on medical need, the system generally excludes uninsurable patients like JM.<sup>3</sup> Relative to other transplant-eligible kidney patients, undocumented patients like JM tend to be healthier, younger, and more likely to have access to living donors.<sup>4</sup> But because organ transplantation is costly and includes lifelong antirejection medications, financial concerns dictate transplant center policies that prevent eligible patients like JM from receiving transplants. In effect, the cost to save a life is valued over human life itself.

While a systemic solution was not apparent in JM's case, we (a group of physicians and students from transplant centers) agreed to ally ourselves with the community as advocates. The community held demonstrations, hunger strikes, and hospital sit-ins. We supported this activism by coordinating with the community, including by providing medical support for the hunger strikers and speaking publicly on their behalf. Ultimately, because of this activism, 8 years after his diagnosis, JM was transplanted with his mother's donated kidney.

Simultaneously, we convened a taskforce with the community and transplant center leaders. We engaged the Latino caucus of the state's legislature, and a law—the first in the nation—was passed to provide uninsured residents of the state access to organ transplantation.<sup>3</sup> The regional organ procurement organization also established a fund to purchase insurance to help cover costs of patients' posttransplant care. In the first 6 years, this fund has allowed over 200 undocumented, uninsured patients to undergo organ transplantation across the state of Illinois, with 150 more on the waiting list (personal communication, J. K. Cmunt, Illinois Transplant Fund, November 23, 2021).<sup>5</sup> JM has gone on to attend college.

### Commentary

While social justice is a pillar of health care,<sup>6</sup> clinical decision making for uninsured noncitizen patients—particularly for complex and expensive care like organ transplantation—tends to pivot around cost and margin rather than the value of human life, with the exception of the aforementioned law.<sup>3</sup> Physicians face 3 choices in deciding on treatment: (1) accept the status quo, which entails that some patients like JM won't receive treatment; (2) advocate for patients on a case-by-case basis; or (3) imagine and advocate for structural interventions to affect political and social change. The overlapping skill sets of structural competency, allyship, accompaniment, and activism—which together might be viewed as the practice of social medicine—are necessary core competencies of medical practice in the face of an unjust health care system. In analyzing this case of an undocumented patient denied a lifesaving kidney transplant for financial reasons, we highlight the moral obligation of physicians to bring advocacy for needed medical treatments into the public and political space through application of the social medicine skills of structural competency, allyship, accompaniment, and activism.

### Social Health Skills

*Structural competency.* In redressing a health inequity—access to kidney transplantation for uninsured noncitizens in the state of Illinois<sup>6</sup>—advocates applied a structural competency approach, with the understanding that access to care was a systemic problem. Structural competency teaches physicians how social, political, and economic determinants of health cause illness.<sup>7</sup> This approach, which focuses on the forces that influence health outcomes beyond the individual encounter, consists of 5 core competencies: (1) recognizing how structures like racism and other forms of marginalization shape clinical interactions; (2) “developing an extra-clinical language of structure”; (3) “rearticulating ‘cultural’ formulations in structural terms”; (4) “observing and imagining structural interventions”; and (5) “developing structural humility”—the awareness that professionals must be led by the community to solve problems.<sup>7</sup> However, the structural competency approach is inadequate without applying the skills of allyship, accompaniment, and activism.

*Allyship and accompaniment.* Allyship is an intentional practice in which persons in positions of privilege and power build authentic relationships with marginalized groups based on trust, consistency, and accountability in order to address unjust power structures in a manner that the community can recognize, acknowledge, and name. We were able to build trust by showing up consistently in the community at meetings and gatherings while amplifying the community's demands in public and political spaces, as well as within the transplant health centers by convening a task force.<sup>5</sup> Related to allyship, Paul Farmer speaks of physicians' obligations to practice accompaniment, an ethical value expressed in actions of pragmatic solidarity with the community.<sup>8</sup> In practicing accompaniment, health care practitioners are present with a patient or community during a journey toward equity. Similar to allyship, accompaniment is a deeper form of commitment to change.<sup>8</sup> It does not prioritize a physician's technical expertise above solidarity, compassion, or willingness to acknowledge and respond to inequity in a community, and the physician is not released from this obligation until the community makes that decision. For us, the Chicago physicians advocating for undocumented immigrants' access to transplantation, accompaniment meant committing to years of struggle in solidarity with the community with no obvious solution in sight. It also created urgency for physician advocates to partner with community leaders, transplant centers, and politicians to resolve a seemingly intractable problem.

*Activism.* In effect, activism is a natural consequence of the decision to be allies and *accompagneurs* after applying a structural competency analysis to the problem. Activism requires health professionals to publicly leverage their privilege for social change. In this case, activism meant showing up at demonstrations at the transplant centers, convening meetings with the demonstrators and transplant leaders, and being vocal supporters for the petitioners in the media and in dialogue with political leaders.<sup>3</sup>

If the social medicine skills of allyship, accompaniment, and activism are necessary to achieve morally appropriate health outcomes for our patients, why are they not more widely practiced? There are 2 major reasons: (1) practitioners' concern that their activities on behalf of the community could cause risk to themselves and their institutions; and (2) practitioners' resistance to activism—arising from ideological opposition, lack of experience, or the belief that activism is beyond the scope of medical practice.

### **Individual and Organizational Risk**

While the World Health Organization has defined health care as a human right,<sup>9</sup> in the United States, access to health care is, in practice, not a human right. Most hospitals operate within the parameters of a racialized capitalist system,<sup>10</sup> wherein the financial bottom line can drive clinical decision making. As Black and Latinx communities are disproportionately more likely than White communities to be uninsured or on government insurance that reimburses more poorly than private insurance, decisions about access to care have become racialized. Most physicians have been trained to comply with the economically determined rules of their organizations, and this passivity can perpetuate structural racism and other inequities.

In this case, the group seeking redress in Chicago comprised uninsured Latinx patients who were denied appointments for transplant evaluation. Clinicians and administrators were reluctant to take a stance on behalf of the transplant petitioners, as doing so could have jeopardized their hospital financial position.<sup>2,3</sup> The average kidney transplant direct surgical costs and charges for extensive follow-up care and monitoring are estimated to



be over \$400 000.<sup>11</sup> Furthermore, if patients cannot adhere to the necessary **clinic follow-up and medications** due to a lack of insurance, the transplanted kidney could fail, thereby jeopardizing the reputation of the transplant program.

### **Resistance**

The practice of social medicine requires physicians to move from being passive participants and de facto defenders of unjust systems to practitioners of the social medicine skills of structural competency, allyship, accompaniment, and activism. There are a number of reasons why doctors might resist embracing this skill set. First, physicians may view themselves as apolitical and intervening on social and political determinants of health care access as outside their domain of influence. They might take refuge in moral relativism, believing that any treatment is better than no treatment and that those with lesser means should get lesser care.

Second, some might disagree fundamentally with the notion that health care—in this case, access to transplantation—is a human right. As the economic class and social background of many physicians are vastly different from those of historically marginalized communities, they are economically and socially more aligned to maintain rather than challenge the status quo.

Third, because most health systems are hierarchically organized, health practitioners who are also employees might view activism as being a potential risk to their employment. Sometimes concerns about employment are explicit, but more often they are implicitly held within the organization and thus deter individuals from pursuing any action deemed risky. These are not trivial concerns, as speaking up and activism might have negative consequences, particularly for those whose race, gender, or position render them more vulnerable to retaliation. At the same time, however, physicians hold some of the most privileged positions within health systems and have disproportionate power to influence change.

Finally, health professionals might feel deterred from practicing allyship, accompaniment, and activism because they do not think that they have the time or the expertise to do so. Time devoted to health activism is often outside the scheduled clinical or administrative hours of most clinicians. Moreover, practitioners might not have expertise in structural competency or have participated in civic activism of any sort. Training in allyship, accompaniment, and activism is not yet central to most medical school and residency curricula. And, in consequence of their lack of training or experience, health professionals may view structural competency, allyship, accompaniment, and activism as beyond the scope of their expertise rather than as a core responsibility. Like all competencies, social medicine skills require practice and repetition, although they are not difficult to grasp and apply. Physicians' lack of training or experience can be rectified by more rigorous training in social medicine concepts during medical education.<sup>12,13</sup>

### **Social Medicine Practice**

For those hesitant about or unfamiliar with social medicine, we suggest the following steps.

*Practice structural competency by speaking out about health injustice.* Learn the structural competency skills to move from individual case reviews to systemic analyses of social and structural root causes of health inequities in your practice. For those

seeking more expertise, begin to practice speaking out about social injustice in health care. Talk to your colleagues. Meet with your leaders. Write op-eds, such as through the OpEd Project's Public Voices Fellowship,<sup>14</sup> and academic papers. Join organizations with health activist agendas like Physicians for a National Health Program.<sup>15</sup> Go to public meetings and testify. Like most things in life, practice makes perfect—including speaking up.

*Engage with community.* Allyship and accompaniment are the natural outcomes of authentic community relationships built and maintained over time. There is a phrase that arose from the disability movement that is apropos of most health activism: “nothing about us without us.”<sup>16</sup> Remember, the role of physician activists is to listen, amplify, and support the needs of the community with humility. With regard to transplant activism, while the system made sense from a financial perspective to those within the transplant centers, it was morally unjust to the patients. Once we understood this community perspective and agreed to accompany community members on their journey, we could advocate more effectively.

*Utilize narrative.* There is power in narrative as well as in data. Narrative + Data + Action = Change is a framework we created that can guide social medicine practice. Social medicine requires that practitioners amplify patients' stories with data and civic activism. The narrative of JM, a 24-year-old uninsured man who had lived in the United States since the age of one and been denied the gift of his mother's kidney simply for financial reasons, amplified the moral case. Data on transplantation demonstrate that Black and Latinx patients are transplanted less frequently than White patients,<sup>17,18</sup> underscoring that the system is unjust. But in this case, civic action in the form of public demonstrations, hunger strikes, creation of the transplant taskforce, and subsequent legislative action was crucial to create the outcome—which improved, but did not completely fix, the system.

*Leverage public policy to create social change.* In this case, law and other policy changes led to expanded access to transplantation. In Illinois, this successful work on transplantation resulted in new legislation, effective December 2020, to extend coverage to undocumented individuals over the age of 65 through the Health Benefits for Immigrant Seniors Program,<sup>19</sup> thereby expanding the social safety net. If there are political determinants of health, activists must pursue political solutions.

## Conclusion

The social medicine skills of structural competency, allyship, accompaniment, and activism are key for health professionals. We have discussed why some clinicians are reluctant to practice activism and provided a roadmap for practicing these skills. JM's case illustrates how activism in service to a community helped a patient equitably access care. Social medicine skills are central to health professionalism. With community members, clinician activists can motivate equity and help all patients get ethically and clinically indicated interventions.

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#### Citation

*AMA J Ethics.* 2022;24(4):E254-260.

#### DOI

10.1001/amajethics.2022.254.

#### Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**How Should US Health Care Meet Latinx Community Health Needs?**

Chiamaka Sonubi, MD, Efren Flores, MD, and Lucy Spalluto, MD, MPH

**Abstract**

This commentary responds to a case about a Latino grocery worker who begins experiencing symptoms but is reluctant to be tested for SARS-CoV-2 and be treated for COVID-19 out of fear of losing his livelihood. The case reveals key weaknesses in US health care system capacity to mount evidence-based responses to mitigate, if not contain, spread of a deadly contagion in vulnerable populations and to care equitably for everyone at risk.

**Case**

Mr S is a 55-year-old Latino man who lives in a 2-bedroom apartment with relatives and supports his family by working in a grocery store. During the COVID-19 pandemic in the United States in 2020, Mr S is an essential worker. He reports symptoms of low-grade fever, chills, cough, shortness of breath, and pleuritic chest pain. When working becomes impossible due to his increasingly severe shortness of breath over 2 weeks, he visits a clinic and is diagnosed with COVID-19. He becomes lethargic as his symptoms become more acute and is transferred by ambulance to a local emergency department, his oxygen saturation now in the low 90s.

Mr S's past medical history includes type 2 diabetes mellitus, obesity (body mass index of 34), hyperlipidemia, hypertension, hypothyroidism, gastroesophageal reflux disease, obstructive sleep apnea, and vitamin D deficiency. A frontal chest radiograph demonstrates bilateral multifocal airspace opacities consistent with multifocal COVID-19 pneumonia. Intensive care unit (ICU) admission with intubation and close monitoring is recommended. Mr S expresses worry, however, about his inadequate insurance coverage, inability to pay for an ICU stay, and not being able to work. Mr S asks to be discharged against medical advice, but eventually agrees to ICU admission for management of COVID-related acute respiratory distress syndrome.

Mr S is intubated for 13 days, during which time his condition is complicated by COVID-related cardiomyopathy and superimposed bacterial pneumonia. He is transferred from the ICU to a general medical floor on day 14. On day 26, Mr S is discharged to a rehabilitation facility.

When Mr S was asked why he did not get evaluated and quarantine as soon as his symptoms started, he responded that the grocery store where he worked remained open

during the COVID-19 pandemic because grocery stores were considered “essential” by the state and that he had no option for remote work. Mr S’s employer did not offer flexible medical leave, and Mr S was concerned that his insurance would not adequately cover the medical costs for an emergency room visit and potential hospitalization at an out-of-network hospital. These concerns were exacerbated by his lack of financial reserve to pay monthly bills and support his family. Mr S concealed his symptoms to keep working and to avoid medical debt.

### Commentary

Societal privilege, or lack thereof, has affected the ability of Latinx individuals to protect themselves from COVID-19 transmission and financially support their families during a global pandemic. Societal privilege results when particular groups benefit and prosper because of the advantages, entitlements, and dominance conferred on them by society.<sup>1</sup> Domains of privilege include gender, race, sexual orientation, socioeconomic status, and religious affiliation. Latinx individuals’ lack of societal privilege has increased the vulnerability of the Latinx community and has resulted in extreme health inequities during the COVID-19 pandemic. As discussed here, layers of vulnerability in the Latinx community include overrepresentation in low-wage work, education gaps and language barriers, financial constraints, social factors and living conditions, and disparate coexisting medical conditions. Current weaknesses in the US health care system (eg, lack of trust, limited health outcomes research in underrepresented populations, and outdated policies that drive inequity) exacerbate these vulnerabilities.

### Layers of Vulnerability in Latinx Communities

*Types of employment.* In response to the COVID-19 pandemic, many states temporarily suspended business to slow viral transmission. While many people were able to work remotely, many like Mr S were deemed essential by states and required to continue working to provide services outside their homes, which helped social functioning but inequitably increased their exposure to SARS-CoV-2. Although social distancing and self-isolation recommendations were supported by the Centers for Disease Control and Prevention (CDC),<sup>2</sup> paid sick leave and working remotely were not options for many workers.<sup>3</sup>

Vulnerable populations, including Latinx communities, are overrepresented in this low-wage public-facing workforce (eg, transportation, food, and agriculture) and are more likely to be exposed to the virus.<sup>4</sup> Historically, non-White populations have been driven into low-wage employment with little flexibility in work hours and little or no paid time off. Specifically, prior to the pandemic, only 16.2% of Latinx workers held jobs that would allow for remote work compared to 31.4% of non-Latinx workers.<sup>5</sup>

*Education and language barriers.* Latinx individuals are half as likely to hold a college degree as non-Latinx White adults.<sup>6</sup> This widening educational divide contributes to the aforementioned overrepresentation of Latinx individuals in low-wage jobs with little flexibility. The educational gap is further exacerbated by the scarcity of policies and programs to support the advancement and financial stability of low-wage workers, as demonstrated by the weak enforcement of antidiscrimination laws and the dearth of organizational initiatives to improve worker skills and promote good jobs through economic and workforce development.<sup>7</sup> Furthermore, 28.4% of Latinx individuals are not fluent in English, and 71% of Latinx individuals speak a language other than English at home.<sup>8</sup> This **lack of full fluency in English** can decrease access to health care, impair

delivery of high-quality care, increase length of inpatient stays, and result in worse health outcomes.<sup>9</sup>

*Financial constraints.* Mr S's financial circumstances mirror those of the majority of Latinx adults in the United States. Many Latinx families are under marked financial pressures, with the poverty rate for Latinx individuals being nearly double that for non-Latinx Whites (19.4% vs 9.6%, respectively).<sup>5</sup> Approximately 70% of Latinx adults in the United States do not have emergency funds to cover 3 months of expenses.<sup>10</sup> Added financial strains of the pandemic have forced many to choose between continuing to work while infected or staying home without income.

Mr S's avoidance of medical care due to his lack of insurance and fear of mounting medical cost is not uncommon. Many Latinx individuals cannot afford health insurance, and those who can are often underinsured and forced to pay out-of-pocket expenses that are unaffordable and continue to increase over time.<sup>11</sup> Latinx individuals have the lowest rates of health insurance of all racial or ethnic groups in the United States except American Indians/Alaska Natives.<sup>11</sup> In 2018, 26.7% of Latinx adults ages 18 to 64 were uninsured, compared to only 9.0% of non-Latinx Whites.<sup>12</sup> In 2019, approximately 21% of Latinx adults ages 18 and older in the United States went without care due to costs.<sup>13</sup>

*Social factors and living conditions.* Like Mr S, many Latinx families live in multigenerational homes that make it difficult to isolate and social distance in the event of a positive COVID-19 test.<sup>14</sup> These more crowded living conditions for the Latinx community might also increase vulnerability to the virus, making even a decision to stay home risky. Furthermore, Latinx individuals are overrepresented in congregate settings, such as prisons,<sup>15</sup> which can further increase risk exposure and limit one's ability to keep distant, per CDC recommendations.<sup>16</sup>

*Coexisting medical conditions.* Like Mr S, many Latinx individuals may be more susceptible to severe cases of COVID-19 because of coexisting medical conditions. Specifically, Latinx individuals diagnosed with COVID-19 have higher rates of hospitalization and ICU admission than White individuals, regardless of whether they had coexisting medical conditions such as hypertension, cardiovascular disease, kidney disease, or diabetes.<sup>17</sup> The layers of vulnerability in the Latinx community, including presence of coexisting medical conditions, result in higher COVID-19 morbidity and mortality in the Latinx community. Specifically, in November 2021, the rates of COVID-19 mortality, hospitalizations, and cases in Latinx individuals were 2.1 times, 2.5 times, and 1.6 times higher, respectively, than those of non-Latinx Whites.<sup>18</sup>

### **Reorganizing US Health Care**

While the US health care system cannot undo what has been done, the system must begin to address the complex combination of economic, physical, and social forces undermining the health of Latinx communities in the midst of this public health crisis. The case of Mr S serves to highlight the disproportionate impact that these combined factors can have on one's decision to pursue, avoid, or delay health care.

This inequity prompts us to wonder, *How should the US health care system be restructured to meet the needs of the Latinx community during and after the COVID-19 pandemic?* To begin, the US health care system must urgently acknowledge its current inability to provide high-quality care for vulnerable populations. It must recognize that the health care crises faced by individuals such as Mr S are not isolated incidents.

Rather, these all-too-common events in combination represent a pervasive threat to the overall health of the nation. A pandemic cannot be controlled if certain portions of the population are made, and then left, vulnerable to illness.

Practical initial steps for the US health care system to take to achieve more equitable care for vulnerable populations include building trust with vulnerable populations, improving data collection on health outcomes in underrepresented populations, increasing research funding for studies dedicated to improving equitable care, and driving policy change to make health care affordable and accessible for everyone.<sup>5,19</sup> Such policy changes might include offering public options for health insurance, expanding Medicaid coverage in all states, lowering consumer costs for medical care, providing nonemergency transportation for medical care, and having **community health workers** or navigators available.<sup>20</sup>

One challenge in reorganizing US health care lies in implementing the monumental changes necessary to make lasting impact. Lasting impact can only be made when both the US health care system and society dismantle the existing system of social privilege, combat centuries of structural racism, and overcome cultural and socioeconomic inequities in access to health care.<sup>5</sup>

### Conclusion

COVID-19 has laid bare health inequity in Latinx communities that is closely linked with lack of social privilege, low-paid public-facing employment, substandard housing, lower level of education, language barriers, and financial constraints. To address health inequity, US health care must acknowledge its weaknesses and welcome the challenge of redesigning health care delivery from the top down through the lens of health equity. Changing existing systems of social privilege, structural racism, and socioeconomic inequity are critical to health care reform success.

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#### Citation

*AMA J Ethics.* 2022;24(4):E261-266.

#### DOI

10.1001/amajethics.2022.261.

#### Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

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## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E267-274

### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

#### What Should Count as Best Practices of Forensic Medical and Psychological Evaluations for Children Seeking Asylum?

Maria Joy Ferrera, PhD, LCSW and Minal Giri, MD

##### Abstract

The process of being granted asylum is complex, often taking months and years. Asylum seekers face high risk of being denied asylum in the United States. As medical and psychological evaluations assist in achieving successful asylum outcomes, human rights asylum clinics are being established throughout the country to facilitate these types of evaluations. The Midwest Human Rights Consortium, a multi-institutional, interdisciplinary initiative, is working to streamline the referral process and increase the evaluator workforce through training and mentorship of practitioners. More work is needed to establish evidence-based, child-centered, and trauma-informed best practices in training evaluators and performing evaluations.

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##### Case

AA was 17 years old when his attorney referred him for a psychological forensic asylum evaluation. He is one of many such individuals interviewed during years-long processes of conducting such evaluations. He was born in a Central American country and arrived in the United States during the prior year. He left his home due to gang violence and believed his life would be in danger if he returned. He was transferred from a US Customs and Border Protection (CBP) detention center to a shelter under contract with the US Department of Health and Human Services Office of Refugee Resettlement (ORR), which aims to assist and provide resources to refugees, asylum seekers, and newly arrived immigrants to the United States. Following eventual release to a sponsor, who must be a US citizen or legal permanent resident who agrees to offer food, shelter, health care, and other necessities for at least 6 months,<sup>1</sup> and who, in this case, is a trusted friend of AA's family, AA awaits a response to his asylum application.

When AA was 9, his mother's boyfriend beat him severely and frequently. Despite numerous calls, police did not intervene, and his mother was unable to protect him. AA left home several times to escape and experienced intermittent homelessness. At age 14, while staying with a friend, AA was threatened with a machete and money was

extorted from him by Mara Salvatrucha (MS-13) gang members. After defending himself against attack by one of the gang members, AA was severely wounded. In danger and without protection, AA journeyed to the United States.

### Commentary

The story of AA mirrors that of thousands of other asylum seekers from the Northern Triangle (El Salvador, Guatemala, and Honduras) who travel thousands of miles to reach the US southern border to escape the threat of MS-13, one of the 2 largest gangs in the Northern Triangle.<sup>2</sup> MS-13 is a transnational gang considered to be a byproduct of civil war, a complex history of US immigration policy, and ongoing Northern Triangle country policies.<sup>3</sup> MS-13 is notorious for its brutality and use of extreme violence.<sup>4</sup> A history of political unrest, corruption, easy access to US-made weapons, the transnational US drug trade, and instability have rendered the Northern Triangle governments unable to protect their citizens from widespread gang violence.<sup>5</sup> AA applied for asylum, a form of protection for anyone who is unable or unwilling to return to their home country and cannot obtain protection in that country due to past persecution or a well-founded fear of being persecuted in the future on account of “race, religion, nationality, membership of a particular social group or political opinion.”<sup>6</sup>

The United States currently has a record number of asylum-seeking youth arriving along the Mexican border.<sup>7</sup> Obtaining asylum is an involved process that includes multiple governmental agencies (eg, CBP, Department of Homeland Security, ORR) and other entities (eg, the immigration court system, community resettlement agencies, **shelters for unaccompanied minors**). Notably, rates of asylum denial have reached record highs, with judges denying close to 74% of asylum cases in fiscal year 2020.<sup>8</sup> The process itself can take years. Illinois, for example, has one of the longest wait times (1404 days on average as of October 2021).<sup>9</sup> Although authorized to stay, asylum seekers are left in limbo without legal status while their cases are pending.

The Midwest Human Rights Consortium (MHRC), a multi-institutional, interdisciplinary initiative, is working to streamline the referral process and increase the evaluator workforce through training and mentorship of practitioners. Drawing from the work of MHRC, the following discussion outlines the complexity of medical and mental health forensic evaluations and the need for establishing clearer guidelines for best practices.

### Medical and Psychological Forensic Evaluations

There is strong evidence that medical and psychological forensic evaluations aid in providing critical evidence of trauma, torture, or abuse that can significantly affect the outcome of unaccompanied children’s asylum cases<sup>10,11,12</sup> and increase the likelihood of being granted asylum.<sup>13,14</sup> The evaluation can also serve to document and raise awareness of issues that necessitate specific resources and services to support the child (eg, mental health treatment and resources, educational supports, and medical care). Despite the inarguable benefits of these evaluations, there is no permanent infrastructure in place to ensure that children have access to them. Although Chicago is a major metropolitan area with numerous immigrant-serving organizations and shelters where unaccompanied children are placed, there was, until recently, no formal system facilitating the critical interdisciplinary collaboration required to offer such evaluations.

To address this need, we established and developed the MHRC. Housed within the Illinois chapter of the American Academy of Pediatrics, this multi-institutional, interdisciplinary initiative has developed a formal referral process that connects

attorneys to evaluators on behalf of their asylum-seeking clients. MHRC also engages in efforts to train and build a workforce of professionals to perform the evaluations and support the establishment of asylum clinics throughout the Chicagoland area.

### **Establishing Standards for Evaluations**

If MHRC is to appropriately evaluate AA, standards should be established in the areas of (1) evidence-based best practices employed in the evaluation process, (2) systematized training, and (3) resources to competently and ethically perform the evaluation.

*Evaluation process.* While the field of asylum medicine is expanding and there are broad guidelines, such as Physicians for Human Rights guidelines<sup>15</sup> and the Istanbul Protocol<sup>16</sup>—both of which deal with evaluating asylees for torture and ill treatment—there is no universal standard of specific assessment criteria when evaluating asylum seekers whose trauma does not fall under the strict definition of torture. In particular, there is a limited framework for evidence-based best practices when working with unaccompanied immigrant children whose claims generally fall outside traditional categories qualifying for asylum. For example, in the absence of state-sanctioned torture and scars, should the court rely on psychological instruments and tools to draw out objective information or information that can be codified?

Working with children also brings up the importance of informed consent. As with all clinical interactions, it is essential to obtain informed consent for performing a forensic evaluation.<sup>17</sup> For children, informed consent requires the approval of the legal representative of the child.<sup>18</sup> However, undocumented, unaccompanied immigrant children are not automatically assigned legal guardians. Who is responsible for providing consent for an unaccompanied child under the age of 18 to participate in a forensic evaluation? Who protects their story and how it is used by the court system or government? Who decides how the child's story should be shared? It is critical to develop an explicit process for gaining a child's consent, regardless of age.

Such questions also raise concerns around data security. The process of conducting the assessment, as well as exchanging information with the attorney and others involved, is fraught with data ownership and security concerns, privacy considerations,<sup>19</sup> and risks of overlooking implications (eg, involving language or communication barriers or manifestations of mental illness). Thus, potentially damaging notes written by a therapist who is not culturally sensitive and who is employed by a governmental shelter may remain in AA's file, affecting the outcome of his case.

The issue of health information privacy as it applies to unaccompanied children is being debated in our legislature.<sup>20</sup> Given rapidly changing technology and commonly used modes of electronic communication, explicit guidelines concerning record protection and information sharing (eg, referral information, drafts of the evaluation) will help protect the privacy of the asylum applicant. Guidelines about the level of detail documented in the file, as well as honoring asylum seekers' wishes concerning whom their file can be shared with and how much information can be shared, should inform best practice standards.

The interview process poses its own challenges. For example, memory distortion<sup>21</sup> due to severe trauma can affect not only applicants' ability to provide a coherent narrative but also their credibility. Memory distortion is particularly a risk for young children who have experienced trauma and disrupted attachments that might affect their neural

development and their social and emotional capacity.<sup>22</sup> In such instances, best standards should require supporting interviews from the child's teachers and caretakers and documentation from their home country if available. Moreover, best practice standards for **interviewing children and asylum seekers** who share their narratives must incorporate a trauma-informed lens, with special attention to how they tell their story and a nuanced understanding of how trauma can impair memory. The kind of information retained in an affidavit also needs to be standardized.

*Training.* MHRC and similar initiatives can increase the evaluator workforce by supporting different evaluation models. Each asylum evaluation model (eg, medical school, academic center, or individual community-practitioner based) presents a unique set of challenges. Ideally, training new forensic assessment evaluators involves opportunities for trainees to observe how evaluations are conducted. However, clients are often unwilling to have observers present. Moreover, there are multiple risks of retraumatization when evaluators ask children to provide the details of their narrative, especially in settings where multiple trainees are involved. While medical school-based clinics are designed to process evaluations expediently, they necessitate the presence of trainees and observers during interviews and examinations of an intimate, emotionally intense, and potentially traumatic nature.

The need for an asylum applicant to disclose sensitive trauma narratives and physical scars to multiple people in a nontherapeutic setting for training purposes should be made transparent, and the evaluation should be structured in the least intrusive way. What guidelines should be incorporated that engage a trauma-informed approach and consider the best interests and rights of the child? Guidelines originally developed for asylum and immigration officers can inform best practice standards that utilize a trauma-informed interview approach, including child-friendly opening statements, building rapport to help the child feel secure, nonadversarial questioning, active listening, and assessing the child's comfort level when speaking with others (eg, parent or family member, observer) in the room and the child's level of fear during the interview.<sup>23</sup> Given the traumatic content of the child's narrative, the evaluator is at risk of experiencing vicarious trauma and thus needs critical self-awareness, self-reflection, and support through mentorship and consultation. This type of support, however, is not always available. Finally, clinicians might be formally trained in forced migration, immigration policy, mental illness, child abuse, or forensic documentation. Training in these areas is not required or regulated, but lack of training can affect an affidavit's quality and client-evaluator interactions.

*Resources.* There is variability in the resources (eg, time, institutional support and funding, physical spaces for the forensic interview, mentorship) available to clinicians to conduct evaluations, which affects systemic capacity to meet the wider demand for evaluations. Depending on the complexity of the case, it can take up to 10 to 20 hours to complete the assessment and write-up. For a community-based practitioner, these labor and time-intensive assessments are usually conducted pro bono or outside normal clinic hours, whereas medical student-run clinics and clinics operating within an academic setting have protected time and infrastructure to offset cost. Academic clinics operating within medical centers and universities that are not student run might offer more experienced clinicians without trainee requirements. However, academic clinics can accommodate only a limited number of clients.

## Conclusion

Aside from the years 2016 to 2020, asylum seekers have been allowed to enter the United States while their claims are being processed.<sup>24</sup> The United States anticipated over 300 000 new asylee and refugee claimants in fiscal year 2021,<sup>25</sup> a number likely to be influenced by—despite efforts to end it—the recently reinstated “Remain in Mexico” policy (ie, Migrant Protection Protocols), whereby asylum seekers wait in Mexico for their cases to be heard in US immigration courts. As of October 2021, a backlog of over 1.4 million immigration cases remains,<sup>26</sup> each requiring legal, social, and health services for asylees and training for officers, health evaluators, attorneys, and judges in trauma-informed care. While the number of US asylum clinics has increased, the field of asylum medicine also continues to grow and evolve.<sup>17</sup>

As MHRC works to strengthen its network and develop best practice standards, it must continue its collaboration with the various professionals and players involved with the asylum evaluation process and continue to use a transdisciplinary lens in gaining consensus on what should be standard best practices in conducting asylum evaluations. While there is evidence that asylum success rates have increased under the current administration,<sup>27</sup> understanding what factors have contributed to these success rates can inform the broader practices of attorneys and evaluators who work with asylees. More specifically, understanding what elements contribute to a stronger forensic asylum evaluation should inform best practices.

Increased dialogue through round tables, conferences, and trainings that involve medical and mental health practitioners, attorneys, judges, and asylees or refugees themselves is critical to promoting a better understanding of the immediate and long-term effects of complex trauma in children who have experienced danger in their home country and are experiencing an ongoing sense of fear. Furthermore, advocating for legislative and structural support and funding to enable increased **legal representation**, evaluator workforce capacity, and implementation of best practices will also be critical. There is much state, national, and international work to be done collectively.

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**Citation**

AMA J Ethics. 2022;24(4):E267-274.

**DOI**

10.1001/amajethics.2022.267.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**How Should Clinicians Express Solidarity With Asylum Seekers at the US-Mexico Border?**

Carlos Martinez, MPH, Lauren Carruth, PhD, Hannah Janeway, MD, Lahra Smith, PhD, Katharine M. Donato, PhD, Carlos Piñones-Rivera, PhD, James Quesada, PhD, and Seth M. Holmes, MD, PhD

**Abstract**

Migrants along the US-Mexico border have been subjected to transnational violence created by international policy, militaristic intervention, and multinational organizational administration of border operations. The COVID-19 pandemic compounded migrants' vulnerabilities and provoked several logistical and ethical problems for US-based clinicians and organizations. This commentary examines how the concept of transnational solidarity facilitates analysis of clinicians' and migrants' shared historical and structural vulnerabilities. This commentary also suggests how actions implemented by one organization in Tijuana, Mexico, could be scaled more broadly for care of migrants and asylum seekers in other transnational health care settings.

**Case**

During the COVID-19 pandemic in 2020, a woman we call SR, an asylum seeker from Honduras accompanied by her 3-year-old daughter, was waylaid in Tijuana, Mexico, in a crowded congregate facility housing 100 migrants, some of whom had already tested positive for the SARS-CoV-2 virus. By mid-April 2020, the state of Baja California in Mexico had registered 500 COVID-19 cases and 50 deaths,<sup>1</sup> but a protocol had not yet been established to manage outbreaks in migrant shelters, and Tijuana's hospital was quickly overwhelmed.

Feeling ill, SR arrived at a free clinic for migrants in Tijuana with low oxygen saturation and a fever. Dr N, a volunteer at the clinic from the United States, reviewed SR's symptoms and test results and diagnosed SR with COVID-19. Resources available to Dr N and other clinicians trying to respond to their increasing numbers of migrant patients seriously ill with COVID-19 were limited, and several clinic staff members who practiced in the United States were prohibited by their San Diego, California-based employers from traveling outside the United States, even just a few miles over the border. The number of clinicians allowed to travel and care for migrant patients across this border diminished daily. Clinicians were deeply troubled by their employers' travel and clinical practice restrictions, and they struggled to decide how they could and should respond.

## Commentary

The clinic to which SR presents is managed by a binational organization, Refugee Health Alliance (RHA), based in Tijuana, Mexico,<sup>2</sup> which offers free health services to members of migrant communities in Baja California. Its founders believe that protecting the well-being of migrants—especially asylum seekers like SR—arriving at the US-Mexico border is a responsibility of US-based clinicians. As discussed below, the clinic embraces an ethic of transnational solidarity in response to enduring, diverse forms of violence that migrants face when crossing international borders.

### Transnational Solidarity in Practice

*Transnationalism* is a widely used framework in the social sciences wherein the nation-state is not the primary unit of analysis.<sup>3</sup> Ramón Saldívar, for example, uses the notion of a “transnational imaginary” to describe the “construction of new spaces for the enactment of politics outside the realm of the purely national.”<sup>4</sup> According to Saldívar, migrants and those inhabiting borderland spaces between, outside, and across nation-state borders consistently develop and redefine a transnational perspective. We therefore suggest that many clinicians providing care to migrant communities in borderland regions have also developed a transnational perspective of a “shared fate” with the patients they serve.<sup>4</sup>

*Solidarity*, another concept with a long lineage in the social sciences, has been described as the feeling and practice of cohesion between individuals and groups.<sup>5,6</sup> Solidarity is undergirded by a common understanding of the mutual interests, responsibilities, and benefits that derive from membership in a social group or coalition. Solidarity can be enacted across categories of social difference through actions that aim to support or advocate for those disproportionately affected by systemic inequalities. Such practices of solidarity differ from acts of charity in their recognition of the histories and social structures that produce and maintain these inequalities.<sup>7</sup>

Transnational solidarity is a foundation of US-based clinicians’ social responsibility to deliver care along international borders, in contrast to global medical humanitarianism efforts deployed, for example, by nongovernmental organizations like Médecins Sans Frontières<sup>8</sup>—with its focus on attending to individuals’ biomedical needs even across contested nation-state borders—and the International Committee of the Red Cross—with its explicit commitment to political neutrality.<sup>9</sup> Transnational solidarity expresses an understanding of shared global histories that have produced recent transnational migrations and reinforced border militarization<sup>10,11,12,13</sup> and expresses opposition to US government efforts to restrict entry to, sanction, or punish asylees and migrants.<sup>14,15</sup> Transnational solidarity as an ethical value also expresses medical neutrality, the view that patients must have unobstructed access to health services regardless of citizenship status or cultural, national, or political background.<sup>16</sup>

Transnational solidarity conceived in this way calls upon clinicians to recognize how social forces and inequities produce patterns of what some scholars and advocates call “structural vulnerability” among patients in borderland regions.<sup>17,18</sup> Structural vulnerability, a concept from the medical social sciences, considers how individuals often relegated to the bottom of social, political, and economic hierarchies experience disproportionately negative health outcomes.<sup>19</sup> International borders themselves can also produce or exacerbate structural vulnerability among certain individuals and groups, such as irregular migrants and asylum seekers, who face disproportionate targeting, policing, deportation, detention, and exploitation during migration.<sup>20</sup> Medical

care and advocacy for patients like SR thus necessitate engagement outside formal clinical spaces and on both sides of international borders—perhaps even in violation of institutional policies.

For example, although Dr N's employer, a US safety-net hospital, prohibited its clinicians from pursuing international travel, Dr N provided pro bono care in Tijuana. Because Dr N's clinical care is grounded in an ethical framework that seeks to redress long-standing transnational harms and inequities that affect migrants' health, clinicians and organizations must work at border sites to bring necessary care and material support to patients lacking international mobility and access to care. In short, health care and advocacy are not *sans frontières*, but transpire because of and in direct response to border militarization and bureaucratization practices that harm migrants.

### **Responses to Transnational Violence**

Asylum seekers along the US-Mexico border have long been subjected to transnational violence brought about by US economic, foreign, and immigration policies as well as by various powerful multinational organizations—from drug cartels to agricultural companies.<sup>3,21,22</sup> These forces are transnational in that they operate across multiple national borders, and they have harmed people in several countries throughout Latin America. As we elucidate below, viewing this continuing violence through a transnational lens demonstrates how the harms that SR faces are rooted in the US government's historical involvement in Latin America and contemporary practices of migrant deterrence.<sup>23,24,25,26</sup>

SR's home country, Honduras, has been a site of perpetual US intervention since the early 20th century.<sup>27</sup> For decades, Honduras' economic and political system have been largely controlled by American-owned agricultural companies, and dozens of US military interventions have been aimed at preserving their commercial interests.<sup>10,11,13</sup>

In recent years, Central America has become a primary drug trafficking route, following US interdiction efforts in the Caribbean.<sup>21,22</sup> In Honduras, these efforts have resulted in escalating violence perpetrated by powerful local gangs with well-known connections to police and some political leaders.<sup>28</sup> Many asylees have fled as a result of widespread human rights abuses under the Honduran government, which continues to have the support of the US government.<sup>29,30</sup>

SR, Dr N's patient, arrived in Tijuana with her 3-year-old daughter in 2018, after she was threatened with violence by a local gang. With the support of a legal advocacy organization, she began the process of applying for asylum in the United States. However, in January 2019, the US Department of Homeland Security (DHS) implemented the Migrant Protection Protocols (MPP).<sup>31</sup> The MPP contravened established domestic and international refugee law by sending asylum seekers like SR back to Mexico to await resolution of their court proceedings, placing them at increased risk for victimization by local gangs, transnational drug cartels, and Mexican security officials.<sup>32</sup> In the wake of the COVID-19 pandemic, asylum trials were postponed, leaving many asylees indefinitely stranded in Mexico.<sup>33</sup>

In addition to DHS implementing the MPP, in August 2021 the Centers for Disease Control and Prevention (CDC) issued an order under Sections 362 and 365 of the Public Health Services Act,<sup>34</sup> which allows border agents to immediately expel migrants attempting to cross into the United States, often preventing them from making an

asylum claim. Ostensibly aimed at defending against the spread of COVID-19, the order flouted international human rights laws and bolstered anti-immigrant rhetoric and a crackdown on the asylum system.<sup>35,36</sup> Meanwhile, due to US pressure, the Mexican government has taken increasingly heavy-handed approaches to asylees.<sup>37,38</sup> Since implementing these policies, many along the US-Mexico border have had to stay in crowded, underresourced shelters or makeshift camps while awaiting court dates.<sup>39</sup> These migrants are also often denied health care in public facilities.<sup>40</sup>

### **Forging Transnational Solidarity**

Although Dr N was prohibited from international travel by his employer, he continued to travel given the urgent needs experienced by asylum seekers and a recognition of the US government's role in amplifying the harms they experienced. Some clinicians' supervisors support efforts like Dr N's, though perhaps begrudgingly. RHA, which manages the clinic employing Dr N, required its clinicians to follow CDC guidelines to reduce risk of transmitting SARS-CoV-2. RHA's work demonstrates how transnational solidarity can help clinicians and organizations navigate ethically complex health care along politically fraught borders. Clinicians can work in solidarity with migrants in some of the following ways.

*Challenge the stigmatization of migrants.* Anti-immigrant rhetoric and policies have stigmatized migrants—especially migrants who do not qualify for asylum—and who, as a result, may be perceived as being less deserving of quality medical care.<sup>41,42</sup> Clinicians can challenge the stigmatization of migrants by interrogating their own negative biases when providing care to migrants. Health professions educators can help students overcome stigmatization by training them in social medicine frameworks, such as structural competency, that acknowledge the impact of US policies on migrant health.<sup>43,44</sup>

*Provide in-person or telehealth care to migrants with limited access to services.* Many organizations are working tirelessly to provide medical care, whether in person or virtually, to migrants and asylees in border regions. Recognizing that many clinicians may not have sympathetic supervisors, Dr N has begun to work with others to organize telemedicine consultations with the support of volunteers in Tijuana. Asylum seekers also must often undergo forensic medical examinations to support their cases. Medical student-run initiatives,<sup>45</sup> such as the asylum clinic launched by the Los Angeles Human Rights Initiative,<sup>46</sup> provide opportunities for clinicians to conduct pro bono forensic evaluations.<sup>45,46</sup> Practitioners should explore similar initiatives in their localities or, if none exist, launch their own.

*Channel critical resources across and along borders.* RHA's clinicians drew upon their networks to deliver important resources across the border, even during a pandemic that restricted clinicians' travel and work. They also mitigated the compounded risks experienced by asylees by supporting shelters in implementing public health measures. For example, Dr N worked with other clinicians and organizations to raise funds so that SR could stay **quarantined in a hotel room** to reduce further spread of COVID-19 at her shelter. With the support of its network, RHA then installed handwashing stations at several shelters and distributed donated personal protective equipment and diagnostic instruments to shelter directors. Through maintaining robust communication with shelters, doctors were able to diagnose several people with COVID-19 and request support from local public health authorities. Clinicians should consider the material and knowledge-based resources they can access through their networks in order to make

those resources accessible to vulnerable communities at the border. Supporting COVID-19 vaccine distribution to migrant communities is also urgent.

*Challenge immigration policy that incurs harm and undermines clinical neutrality.* For example, RHA collaborates with legal organizations seeking to overturn the MPP and CDC order and has joined efforts to protest the inadequate—and at times harmful—health care provided to asylum seekers in US detention centers.<sup>47,48,49</sup> These important partnerships seek to intervene in transnational harm. Thus, the ethics of transnational solidarity guiding the RHA's work serves as a source of creative intervention, collaboration, and commitment to health equity.

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#### Editor's Note

This research was approved by the institutional review board of the Committee for Protection of Human Subjects at the University of California, San Francisco, on July 15, 2020.

#### Citation

*AMA J Ethics.* 2022;24(4):E275-282.

#### DOI

10.1001/amajethics.2022.275.

#### Conflict of Interest Disclosure

Dr Janeway is the co-founder and co-director of the nonprofit Refugee Health Alliance. The other authors had no conflicts of interest to disclose.

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**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**How Should Health Equity Researchers Consider Intersections of Race and Ethnicity in Afro-Latino Communities?**

Adolfo G. Cuevas, PhD

**Abstract**

Although Afro-Latinos, or Black Hispanics, bear inequitable burden of disease risks, drivers of health inequity among members of this large Latino subgroup in the United States are understudied. This article proposes avenues for more rigorous research on how racial diversity within Latino populations is key to generating better understandings of mechanisms and causes of racial health inequity in US Latino communities.

**Case**

Mr V and Mr R have known each other from childhood in Gaunabo, a seaside area of Havana, and emigrated from Cuba to pursue lives in the United States. Both men's skin color influenced their ethno-racial identity formation and assimilation experiences over time. Mr V has light skin, self-identifies as White, resides in a suburban neighborhood, and draws steady income from a job that fuels his upward social mobility in the American middle class. Mr R has dark skin, self-identifies as Afro-Latino and Black, and lives in a community that he and his neighbors regard as a refuge from racial discrimination.<sup>1</sup> Living with other Black community members has enabled his learning of a vocabulary that helps him forge meaning from painful, routine experiences of racial discrimination in the United States.

**Commentary**

This story of divergence is not rare for Latinos. In a race-conscious society like the United States, racism and colorism<sup>2</sup> have profound effects on Latinos' life chances and health. This article discusses potential mechanisms and causes of health inequities within the US Latino population. Key to understanding experiences of discrimination and patterns of minoritization that arise within or between Latino communities, influence individual and community identity formation, and shape individual and community assimilation experiences is the distinction between first-person and third-person perceptions and identifications of membership in racial and ethnic groups. First, public health researchers use the terms *Hispanics*, *Latinos/Latinas*, and *Latinx* to refer to Spanish-speaking persons with Latin American and Caribbean origins. For the sake of consistency, this article uses the term *Latinos* to refer to individuals who, though viewed by some as a monolithic group in the United States, express heterogeneity (eg, in

national origin, culture, history of Indigenous colonization or African enslavement, socioeconomic and immigration status, and length of US residence) that is important to recognize and fairly represent in Latino health discourse and research.<sup>2,3,4</sup> Second, the terms *race* and *ethnicity* are not mutually exclusive and deserve clarification. *Race* is a social construction standardly used to categorize human beings according to phenotypic (ie, physically visible) characteristics (eg, skin color, facial features, hair color). *Ethnicity* is also a socially and anthropologically derived tool used to describe human beings' cultures, values, and ways of living and making meaning.<sup>5</sup>

Despite growing recognition of racial and ethnic heterogeneity in US Latino populations, the health of Afro-Latinos, also known as Black-Latinos or Black-Hispanics, has been largely neglected in the public health and health equity literatures. Afro-Latinos are individuals of both Latin American origin and African ancestry, many of whom identify racially as Black and ethnically as Latino. As of 2020, the US census estimates that Latinos who identify as Black account for approximately 2% of the total US Latino population (or roughly 1.2 million persons).<sup>6</sup> Dominicans, Puerto Ricans, and Cubans are more likely to identify as Black than other Latin American groups.<sup>7</sup> These official estimates, however, might underestimate actual numbers of Afro-Latinos in the United States. Most Latinos, particularly Latino immigrants, reject racial categories used by the US Census Bureau.<sup>3,8,9,10</sup> The Pew Research Center suggests that the actual number of Afro-Latinos could be higher than reported in surveys asking about race. Among 1520 Latino respondents, only 8% reported their race as Black, but 24% considered themselves to be Afro-Latino.<sup>11</sup> This latter estimate closely reflects the proportion of Latinos who self-identify as Afro-Latino or who have African ancestry in Latin America (29%).<sup>11</sup> We can surmise, based on the Pew survey and the US census,<sup>12</sup> that there are more than 17 million Afro-Latinos residing in the United States. These numbers will rise as the overall Latino population continues to grow during ensuing decades. Thus, a single grouping of Latinos prevents us from understanding the health profile and risks of a large segment of the Latino population.

### **Strengthening Afro-Latino Equity Research**

Overall, Latinos tend to have health outcomes that are better than those of their non-Latino White counterparts, despite having lower average income and education. This phenomenon is commonly known as the Hispanic paradox.<sup>4</sup> However, this paradox does not apply to Afro-Latinos. Afro-Latinos have a shorter life expectancy than both their White Latino counterparts and non-Latino White Americans.<sup>13</sup> Among Latinos, only White Latinos have a longer life expectancy than non-Latino White Americans.<sup>13</sup> In fact, emerging research suggests that differences between Afro-Latinos and White Latinos with respect to life expectancy and health mirror those of non-Hispanic Black and non-Hispanic White Americans.<sup>3,4</sup> Pregnant Afro-Latinas are at greater risk of experiencing preterm birth and having newborns that are of low birth weight and small for their gestational age compared to White Latinas.<sup>14</sup> Afro-Latinos are also more likely to rate their health as fair or poor,<sup>15</sup> have higher self-reported hypertension,<sup>16</sup> and report higher levels of depressive symptoms<sup>17,18</sup> than their White Latino counterparts, and Afro-Latino women have higher body mass index (BMI) than White Latinas.<sup>19</sup> Nevertheless, there remains a paucity of research assessing **racial inequities** among Latinos across different dimensions of health. Despite extant but scarce evidence, we know even less about drivers of racialized health inequity among Latinos.

Borrell<sup>4</sup> posits that in a society that stigmatizes and disadvantages dark skin, Afro-Latinos—depending on how they are categorized—are channeled towards or away from

environments and circumstances that negatively influence life chances and health outcomes. These inequities are manifest at 3 levels of analysis: contextual, interpersonal, and individual. Significant research is needed at each level to elucidate the causes and consequences of racial health inequities among Latinos.

*Contextual.* Institutions and policies play a central role in maintaining racial health inequities through unequal distribution of resources, opportunities, and risks by race.<sup>20</sup> For instance, racial segregation is a cornerstone of racial inequities in health. The physical separation of the races that was imposed by legislation and supported by the judicial system in decades past remains intact and imposes a disproportionate burden on Black Americans today—despite the **legal ending of segregation** in 1964.<sup>21</sup> As such, Black Americans are more racially segregated than any other racial or ethnic group today and thus experience truncated socioeconomic mobility, stunted employment opportunities, poor quality education, and disproportionate exposure to environmental risks (eg, violence, toxins, and hazards).

In what is known as the weathering hypothesis, chronic exposure to social and economic adversities can lead to multisystem physiological dysregulation early in life and, in turn, increase the risk of multiple chronic conditions and premature mortality.<sup>22,23,24</sup> As one example of socioeconomic adversity, Afro-Latinos are more likely to live in racially segregated Black neighborhoods with a higher share of poor residents and a lower share of homeowners than White Latinos.<sup>20,21,22</sup> Recent research documents that homes owned by Afro-Latinos are valued lower than homes owned by White Latinos.<sup>22</sup> Yet the effects of housing and other socioeconomic adversities on racial health inequities among Latinos remain markedly understudied. More research is needed to identify and quantify the specific structural indicators that contribute to racial health inequities. A greater understanding in this area could lead to comprehensive anti-Black racism policies that aim to improve population health for African Americans and Afro-Latinos.

*Interpersonal.* Structural racism reinforces a culture of racism that, in turn, bolsters prejudice and discrimination at the interpersonal level.<sup>23</sup> Afro-Latinos (and darker-skinned Latinos) are exposed to more discriminatory events than White Latinos. For instance, Afro-Latinos experience more labor market and housing discrimination than do White Latinos.<sup>24,25</sup> Afro-Latinos are also more likely to experience major discrimination (eg, being treated unfairly by police) and daily discrimination (eg, being treated with less courtesy) than their lighter-skinned Latino counterparts,<sup>7,26</sup> and darker-skinned Puerto Ricans exposed to more major forms of discrimination have greater multisystem physiological dysregulation than lighter-skinned Puerto Ricans.<sup>26</sup> There is a need to investigate race-related psychosocial factors (eg, colorism, internalized racism) and non-race-related psychosocial factors (eg, financial stressors, occupational stressors) to promote better understanding of more proximal population health determinants and to enhance influence of public health policy changes.

*Individual.* There is a need for epidemiological studies to include more diverse samples of Latinos to better assess patterns of disease across racial groups. Previous studies have assessed a few health outcomes (eg, BMI,<sup>19</sup> depression,<sup>17,18</sup> and blood pressure<sup>16</sup>) in diverse samples of Latinos. Researchers should investigate a wider range of health outcomes, including preclinical indicators of disease and indicators of physiological functioning and aging. Furthermore, the meaning of and attitude toward race and racial categories vary by country of origin, nativity status, and level of acculturation. Epidemiological studies should consider using multidimensional race responses (eg,

socially assigned race) and multiracial categories (eg, mestizo, mulatto, Afro-Latino) to improve our understanding of the sociocultural influence of race on health. Lastly, epidemiological studies might consider including skin color measures, as they help capture features of colorism that standard race and racism questions do not.

### Conclusion

Since Afro-Latinos (and darker-skinned Latinos) have worse mental health and physical health outcomes than do White Latinos (and lighter-skinned Latinos),<sup>3,18,27</sup> Latino health researchers and practitioners should study intraracial ethnic differences within Latino populations. While Afro-Latinos still share a culture with White Latinos, they experience unique adversities and challenges in the United States due to racial categorization and discrimination.<sup>4</sup> Unfair treatment disproportionately affects non-Hispanic Black Americans and Afro-Latinos. Yet, despite the call to action by many Afro-Latino scholars,<sup>2,4,5,18</sup> little has been done to better understand causes of racial inequities within the Latino population. There is urgent need to identify racial inequities across multiple dimensions of health, pinpoint root causes of inequities, and determine which social resources can help mitigate them. Achieving these goals requires understanding that racism and colorism affect a large segment of the Latino population.

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**Citation**

AMA J Ethics. 2022;24(4):E283-288.

**DOI**

10.1001/amajethics.2022.283.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**Latino Invisibility in the Pandemic**

Marina Del Rios, MD, Sylvia Puente, Pamela Vergara-Rodriguez, MD, and Noreen Sugrue

**Abstract**

Devastating effects of COVID-19 among Latinos have not been adequately emphasized or addressed by media, public health experts, researchers, or government officials. Moreover, the underreporting of the crisis' effect on Latinos and the undercounting of cases continues even as programs, initiatives, and policies are designed and implemented to mitigate the spread of the virus; to allocate resources to lessen the economic, educational, housing, and nutritional consequences of COVID; and to direct recovery planning. The invisibility and systematic neglect of the Latino population has contributed to Latino individuals' disproportionately high rates of infection, hospitalization, and death. Changing the COVID-19 narrative is necessary in order to ensure appropriate and equitable responses to the pandemic's effect on Latinos.

**Case**

With COVID-19 cases declining in the second quarter of 2021, media attention turned to growing concern over the new COVID patient: White, young, healthy—and hospitalized.<sup>1,2</sup> These headlines erased the reality of the devastating effects of COVID-19 on the Latino community, contradicting what health care workers, family members, and community members have been experiencing since April 2020. Because the Latino population is so much younger than the total population (ie, up to 59% of Latinos vs 46% in the total population are under the age of 35), COVID cases and death from COVID among the young was nothing “new” in the Latino population.<sup>3</sup>

**Commentary**

By May 2021, COVID-19 had infected over 33 million people in the United States, resulting in nearly 600 000 deaths.<sup>3,4,5</sup> While it is often said that “COVID does not discriminate,” the data paint a very different picture. As an example of what is occurring across the country, as of May 31, 2021, about 11% of Illinois' Latino population had been diagnosed with COVID-19 compared to approximately 7% of Illinois' White population.<sup>6,7</sup> Consistent with Latino invisibility, largely ignored is the story that COVID has disproportionately sickened, hospitalized, and killed younger Latinos—essential workers who, because of economic necessity, become sick and die.<sup>8</sup> Age-adjusted

mortality rates expose a largely unrecognized burden: Latinos die at a 2.3 times higher rate than White Americans.<sup>9</sup>

Latinos are also at increased risk for contracting COVID-19.<sup>5</sup> Risk factors include occupational exposure to the virus<sup>3</sup>; residing in multigenerational, overcrowded living spaces<sup>10</sup>; and employment status.<sup>3</sup> Indeed, these factors are better predictors of Latino COVID cases and deaths than underlying health conditions (except heart disease).<sup>3</sup> Moreover, Latinos had the lowest rates of health insurance coverage among all racial or ethnic groups except American Indians/Alaska Natives in 2019.<sup>11</sup> These findings are consistent with socioeconomic status being a significant risk for contracting COVID-19.<sup>12</sup> For the Latino community, long-standing endemic inequity and discrimination have resulted in unacceptably high rates of poverty, educational disadvantage, neighborhood segregation, language discordance, and uncertain citizenship status.<sup>10</sup> The COVID-19 pandemic has exacerbated Latinos' economic distress.<sup>8</sup>

### **Latinos Made Invisible**

In April 2021, a surge of cases and deaths in young, healthy adults in Michigan<sup>13</sup> and a focus on the long-term effects of COVID in children<sup>14</sup> drew the attention of the American public. While these topics deserve attention, in late spring of 2020, another topic had been raised: Latino invisibility. In April 2020, while speaking at a Unidos community forum in Chicago, Aida Giachello, a Latina leader familiar with the devastating impact that COVID-19 was having on younger Latinos, noted that current narratives circulating in the media and in the medical community, as well as statements by public health and other government officials, were incomplete. She went on to note that stories and reports of COVID's effects on Latinos in the context of other communities of color highlighted commonalities but ignored significant differences. And it is those differences (eg, language barriers, documentation status, low level of government relief funds, and multigenerational, overcrowded housing) that largely underlay the disproportionate impact that COVID was having on the Latino community. This observation led her to conclude: "it's as if members of our community are invisible or, even worse, expendable."

One example of Latino invisibility is the phased early vaccine rollout. One goal of vaccine distribution guidelines proposed by the Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention was reduction of COVID-19's disproportionate burdens.<sup>15</sup> A phased rollout prioritizing health care workers and older adults, however, resulted in a disconcerting trend. Instead of creating equity, the **early vaccine rollout** created a disconnect between people's risk of contracting COVID-19 and their access to the vaccine. Latinos were unable to secure early access to vaccines because, while they were overwhelmingly employed as essential workers, they were not in occupational sectors that were the highest priority for early access to the vaccine.<sup>16,17</sup> This meant that they continued to get sick and die due to COVID-19. These essential workers (eg, custodial workers, grocery store workers, delivery personnel), often touted as "heroes," were, at best, invisible and, in some cases, indeed expendable.

Another example of the invisible Latino COVID patient is when municipalities and states began to relax mask-wearing and physical distancing requirements. As the pandemic expanded among young White Americans, levels of COVID exposure among Latino workers in the hospitality industry intensified. In early 2021, behavioral choices produced a startling acceleration in COVID infection numbers among young White Americans taking full advantage of relaxed rules by going to bars and restaurants, as

exemplified by one Illinois bar whose February 2021 opening event was linked to 46 COVID-19 cases.<sup>18</sup> As the mainstream media raised the alarm about these new COVID patients, largely ignored were the increasing rates of COVID infection among young Latinos—the workers in those bars and restaurants who were getting sick and dying.

At the same time that news headlines emerged about deaths of young and White COVID patients, an article appeared in *Vox* on the psychological problems affecting children who lost parents to COVID.<sup>19</sup> The article called attention to the moral imperative to focus on these children and their need for attention and resources, most notably psychological care. As of November 11, 2021, in Illinois, Latinos accounted for about 35% of deaths among those aged 20 to 59.<sup>6</sup> These data underscore the burden of parental loss that Latino children are bearing. And yet the study of children who had lost at least one parent to COVID on which the *Vox* article was based noted only the deaths of parents of non-Hispanic White children and non-Hispanic Black children because it did not include ethnicity as a variable.<sup>14</sup> The *Vox* article therefore fails to mention the moral imperative to examine the needs of Latino children.<sup>19</sup> Once again, we are led to the uncomfortable conclusion that Latinos—and, in this case, also their children—are invisible in the dominant narratives.

### **Policy Implications**

Lord Kelvin noted that if you cannot measure something, you cannot improve it.<sup>20</sup> The invisibility of Latinos leads to misreporting of the true impact of COVID on Latinos, thereby minimizing the presence and consequences of COVID within the Latino community. Latinos' invisibility is likely a significant contributing factor to their disproportionately high rates of cases, hospitalization, and death. Programs, initiatives, and mitigation strategies cannot be targeted to Latinos when relevant measurements fail to be taken. For example, because testing was inadequate in Latino communities across the country, an accurate representation of COVID's spread among Latinos was absent in the spring and summer of 2020.<sup>21</sup> Equitable distribution of resources becomes an elusive goal because the depth of the problem is not reported,<sup>22</sup> and accurate data is difficult to come by as there is no centralized, systematic set of race/ethnicity definitions and reporting requirements. Hospitals, health systems, and local public health entities use different methodologies for collection of data on race/ethnicity.<sup>23</sup> This methodological variation leads to the unfortunate consequence of inaccurate reporting of the incidence and prevalence of COVID among Latinos. The continuation of poor data collection perpetuates Latinos' invisibility, thereby ensuring that Latinos remain at a disproportionately high risk for infection, illness, and death.

Because immigration status has been used as a criterion for eligibility for government assistance, health care assistance programs as well as economic recovery policies implemented in response to the COVID-19 pandemic have been inaccessible to many Latinos and their families. This inaccessibility has no economic justification. For example, considering the tens of billions of dollars in federal, state, and local taxes annually paid by undocumented immigrants,<sup>24</sup> there is no economic justification for immigration status to be a criterion in policy and resource allocation decisions. With approximately 8 million Latinos in the United States—or about 13% of the total Latino population—being undocumented,<sup>25</sup> immigration status has rendered many individuals and families ineligible<sup>26</sup> for federal relief and stimulus dollars, housing assistance, and insurance subsidies through the Affordable Care Act.<sup>22,27</sup>

To ensure that Latinos are rendered visible and that their risk for infection, hospitalization, and death is reduced, we recommend the following actions: enhancing data collection by prioritizing collecting both ethnic and racial data; viewing resource allocation questions through an equity lens to ensure that the **distribution of resources** reflects the presence and impact of COVID; and eliminating immigration status as an eligibility requirement for publicly funded health, housing, and nutritional programs, as well as COVID-related relief payment and programs.

### **Making Latinos Visible**

Unnamed problems produce inequitable solutions, and nowhere is this better illustrated than in the case of Latinos and COVID. The frequent invisibility of Latinos in the COVID narrative—and therefore in policy and resource allocation decisions—underscores the necessity of a call to action. Actions must center on developing a narrative that is inclusive and accurately reflective of the crisis and on developing both data collection methods that capture the realities of COVID's impact on all communities and a set of metrics to gauge if the actions and narratives align to ensure equitable distributive policies. Failing to take up this call to action means that inattention and inequity will continue to define the response to COVID in the Latino community.

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**Citation**

AMA J Ethics. 2022;24(4):E289-295.

**DOI**

10.1001/amajethics.2022.289.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E296-304

### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### Recognizing and Dismantling Raciolinguistic Hierarchies in Latinx Health

Pilar Ortega, MD, Glenn Martínez, PhD, MPH, Marco A. Alemán, MD, Alejandra Zapién-Hidalgo, MD, MPH, and Tiffany M. Shin, MD

##### Abstract

Latinx individuals represent a linguistically and racially diverse, growing US patient population. Raciolinguistics considers intersections of language and race, prioritizes lived experiences of non-English speakers, and can help clinicians more deftly conceptualize heterogeneity and complexity in Latinx health experiences. This article discusses how raciolinguistic hierarchies (ie, practices of attaching social value to some languages but not others) can undermine the quality of Latinx patients' health experiences. This article also offers language-appropriate clinical and educational strategies for promoting health equity.

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##### Raciolinguistics

Hispanic/Latinx (hereafter, Latinx) individuals in the United States represent a culturally, racially, and linguistically diverse and rapidly growing population. Attempting to categorize all Latinx individuals in a single homogeneous group may result in inappropriate stereotyping,<sup>1</sup> inaccurate counting,<sup>2,3</sup> ineffective health interventions that insufficiently target at-risk subgroups,<sup>4</sup> and suboptimal health communication.<sup>5</sup> A more helpful approach is to use raciolinguistics to conceptualize the heterogeneous, complex Latinx experience as it relates to health. Raciolinguistics is the study of the historical and contemporary co-naturalization of race and language and their intertwining in the identities of individuals and communities. As an emerging field that grapples with the intersectionality of language and race, raciolinguistics provides a unique perspective on the lived experiences of people who speak non-English languages and people of color.<sup>6</sup> As such, understanding raciolinguistics is relevant to providing language-concordant care<sup>7</sup> to patients with limited English proficiency (LEP), who have been historically marginalized by structural barriers, racism, and other forms of discrimination in health care.

In this manuscript, we explore how raciolinguistics can help clinicians to appropriately conceptualize the heterogeneous, complex Latinx experience as it relates to health care. We then use the raciolinguistic perspective to inform strategies to dismantle structural



barriers to health equity for Latinx patients pertaining to (1) Latinx patients' health care experiences and (2) medical education.

### **Raciolinguistic Latinx Experiences**

Sociological understandings of “race” presume that race is a social construction in which biological and other features serve as indices of societal values and generate enduring racial logics (ie, the use of race to define an individual or community's social structure or status).<sup>8,9</sup> While not a race in the phenotypic sense, Latinx people have been racialized in the United States following a pattern similar to that of other minoritized groups.<sup>10,11</sup> Like race, “ethnicity” is a socially constructed category; depending on the context, the term *ethnicity* may refer to an individual's culture, heritage, ancestry, or national origin.<sup>12</sup> Although governmental classifications, such as in the US census, refer to “Hispanic or Latino” as an ethnicity,<sup>13</sup> persons who identify (or are labeled) as Latinx may be of multiple races, nationalities, ethnicities, or cultural or linguistic backgrounds.

Language is a salient feature of the racial formation of Latinx and other groups. Early research on linguistic profiling demonstrated that racial discrimination is often predicated on the sound of one's voice and the images that those sounds conjure in the imagination of an interlocutor.<sup>14</sup> This research suggested that particular linguistic forms are linked to particular racialized phenotypic characteristics, which, in turn, index societal values and perceptions. Recent research on the relationship between language and race, however, moves beyond this early theorizing and argues not that language indexes race but rather that language and race have become co-naturalized.<sup>7</sup> In this way, saying that someone “sounds Mexican” is not an objective appraisal of speech but rather a subjective “racing” of that person. In other words, to say that someone “sounds Mexican” is to place that person in the category *Mexican* and, at the same time, to foreground the societal values and perceptions of “Mexican” people.

A raciolinguistic perspective opens new understandings of the social meanings attached to languages and varieties of language in the United States and beyond.<sup>6</sup> It has long been established that no single language or variety of a language is superior to or more complex than any other but, instead, that all languages and varieties serve their users equally well to express themselves, and all constitute rule-governed systems.<sup>15,16</sup> Even so, not all languages and varieties enjoy the same social prestige.<sup>17</sup> The values attached to speakers of a language often overlap with the very same values attached to them as part of a racialized group,<sup>18</sup> resulting in intersecting social perceptions of race and language “experienced in powerfully embodied and perceivable ways.”<sup>19</sup>

Central to the formation and maintenance of raciolinguistic hierarchies is the concept of the listening subject.<sup>7</sup> Raciolinguistic hierarchies are maintained not so much because speakers choose to speak in one way or another but rather because listeners choose to listen in particular ways. Let us consider again our initial example: “you sound Mexican.” While this may ostensibly be an observation about how someone else speaks, it is actually more revealing of the way the person who says it *hears*. “You sound Mexican” is always equal to “you sound Mexican to me.” Understanding raciolinguistic hierarchies in health care allows for recognition and a deeper understanding of structural barriers to Latinx health equity.

## Improving Latinx Health Experiences

Raciolinguistic hierarchies have been documented in the health care experiences of US Latinx and limited English proficiency (LEP) populations.<sup>20,21,22,23</sup> For example, a study of 20 Latinx immigrant women in 2 community health centers in Utah found that patients reported often being the target of discrimination because of the way they looked or spoke.<sup>22</sup> One participant commented: “I was often made to wait for hours, just sitting there, while other white people were tended to first.”<sup>22</sup> Another study of the health care experiences of Latinx mothers in Detroit and Baltimore found that the perception of discrimination was heightened by the “battle” to manage language barriers.<sup>23</sup> The cumulative exposure to **discrimination across generations** may result in long-lasting negative health consequences for the US-born children of Latinx immigrants.<sup>24</sup>

Conversely, increasing the number of linguistically and culturally concordant physicians might attenuate perceptions of discrimination and “othering” in health care. Patients with LEP and type 2 diabetes are less likely to perceive discrimination when treated by a language-concordant clinician.<sup>25</sup> Similarly, Latinx patients treated by a Latinx mental health professional reported improved communication and a stronger working alliance.<sup>26</sup> Strategies to dismantle raciolinguistic hierarchies in health care also should include thoughtful attention to posting multilingual signage, hiring patient navigators, providing multilingual patient information, ensuring language-appropriate access to scheduling and digital health platforms (eg, telemedicine), engaging with Latinx populations through community health worker programs, and partnering with professional medical interpreters (see Table). Signage and written material should reflect the language of the target population rather than **jargon** that may not be easily understood.

**Table.** Manifestations of Raciolinguistic Concepts in Health Care and Proposed Solutions to Improve the Latinx Health Care Experience and Medical Education

Raciolinguistic Concept	Manifestation of Raciolinguistic Concept in Health Care	Example of Problem	Proposed Solution
Racial logics	Interaction and intersectionality of race, language, ethnicity, and national origin	<p>Patients who are non-English speakers are perceived to be health illiterate.</p> <p>An individual who self-identifies as Latinx is assumed to be “White” based on their physical appearance upon hospital registration.</p>	<p>Critically review educational cases to ensure thoughtful representation of Latinx patients of varied nationalities, races, and educational level.</p> <p>Engage with Latinx community organizations to better understand community language and health literacy needs and/or create joint programs (eg, with patient navigators, community health workers).</p> <p>Ensure electronic health record systems have user-friendly fields to facilitate accurate language documentation.<sup>27</sup></p>
Raciolinguistic hierarchies	Microaggressions	<p>A medical student with a “Spanish-sounding” name is asked to interpret during a medical encounter with a Spanish-speaking patient.</p> <p>Signage or forms are translated into Spanish but include medical jargon and language structures that are not well understood by the target population.</p>	<p>Establish clear health system policies regarding professional interpreter use.<sup>28</sup></p> <p>Make professional interpreters accessible and train staff to work with them.<sup>28</sup></p> <p>Review written materials and educational resources in non-English languages for readability level and engage community members and organizations for feedback on comprehension.</p>

Listening subjects	Implicit bias	A patient is assumed to have certain cultural health beliefs based on their ancestry, race, or language and is not offered a specific health service (eg, oral contraceptives, vaccination, colonoscopy) because it is assumed the patient will refuse.	Train staff to consistently and respectfully ask patients about language preference (eg, “What language do you prefer we use for today’s visit?” or “In what language would you be most comfortable for this visit?”) <sup>2</sup>
		Some varieties of Spanish are judged to be better or more valid than others.	Develop clinical cases that reflect authentic Latinx experiences and varied cultural beliefs and practices rather than stereotypes.
			Involve Spanish speakers who reflect multiple varieties of Spanish in courses as teaching assistants, guest speakers, or pre-recorded audios or videos.

Latinx patients may preferentially speak a variety of languages. Recent data show that 38% of US Latinx individuals mainly speak Spanish and 36% use both Spanish and English (at variable skill levels), whereas 25% mainly use English.<sup>29</sup> Yet Spanish speakers compose 64% of US individuals with LEP,<sup>30</sup> and one-third of US Latinx individuals ages 5 and older report difficulty communicating in English.<sup>31</sup> Other language preferences of US Latinx subgroups that are not as well studied include Portuguese, Indigenous languages (eg, Mayan, Quechua), or a combination of languages (eg, Spanglish). Despite diverse language needs, Latinx individuals may feel pressured to select “English-speaking” on medical forms due to discrimination fears, or they may be labeled as English-speaking if they are accompanied by an English-speaking family member. Such incorrect labeling may result in underrecognizing the need for onsite professional medical interpreters—an evidence-based intervention that significantly improves communication, patient outcomes, patient satisfaction, and health care utilization.<sup>32</sup> To dismantle raciolinguistic hierarchies in Latinx patient care, health care centers must ensure that staff are trained in clear policies and procedures regarding accurate, consistent, and respectful collection of demographic information, including language preference,<sup>2,27</sup> and that patients and staff can easily access professional language services<sup>28</sup> (see Table).

### Improving Education by Applying Raciolinguistics

Strategies to teach patient-centered communication skills with ethnic, racial, and linguistically diverse groups, such as unconscious bias training and medical Spanish courses, are in increased demand in medical education.<sup>33,34</sup> However, curricular materials may unintentionally reinforce raciolinguistic hierarchies, stereotypes, and implicit bias by predisposing learners to view Spanish speakers through the lens of myriad social problems, such as alcoholism, teen pregnancy, poverty, health illiteracy, and incarceration.<sup>35</sup> For example, while it would be useful for some medical Spanish role plays to illustrate Latinx patients with low health literacy, it would be more valuable to teach how clinicians should respectfully evaluate the educational level of Spanish speakers and adjust their communication register accordingly. Similarly, while some Latinx patients may express cultural reasons for refusing a medical recommendation, it would be inappropriate and inaccurate for all or most simulated encounters to reflect Spanish-speaking patients refusing care; this stereotype could perpetuate incorrect attribution of a cultural belief and deter clinicians from offering indicated services that they believe will be refused. Some data show that non-English speakers are less likely to receive a recommendation from their physician for potentially lifesaving health services, such as colorectal cancer screening.<sup>36</sup> Medical education should broaden and enrich learners’ understanding of the heterogenous, diverse Spanish-speaking population

rather than restrict language skills application to basic patterns that are often inaccurate.

Additionally, clinical communication skills training focusing on the needs of minoritized groups, such as non-English speakers, is often limited to students who specifically seek **electives related to improving language** or cultural skills (eg, medical Spanish courses or study abroad clerkships).<sup>37</sup> However, given trends in US demographic data, all clinicians, regardless of their preexisting language or cultural skills, should be equipped to care for linguistically diverse populations.<sup>38</sup>

Among potential strategies for remedying racial inequities, Fair and Johnson recommend rigorously analyzing the use of race in clinical tools and practices, medical education, and research and centering communities' voices in health interventions.<sup>39</sup> Naming racism<sup>39</sup> and "intersecting forms of oppression,"<sup>40</sup> such as discrimination against patients who prefer non-English languages, is critical to making the needed educational and health care systems changes to ensure quality care for Latinx individuals. Analyzing medical education through a Latinx lens requires addressing the intersectionality of race and language and ensuring that it is appropriately reflected in educational materials (see Table). For example, schools should review their curricula, particularly in clinical skills, patient cases, and content about social determinants of health or health inequities to identify where and how the Latinx community is represented.

Next, educators should examine how teaching materials portray Latinx patients and make adjustments as needed. For example, materials should not portray immigrants negatively and all non-English speakers as having low health literacy. Educators should consider modifying materials and rosters of standardized patients to reflect raciolinguistic diversity. For instance, in the cardiac block, a clinical scenario could be added in which a student's task is to interview a patient with LEP who presents with chest pain. Diverse actors, when empowered, can provide a valuable community perspective that ensures that language varieties, cultural beliefs and practices, and other elements of a case are authentic rather than stereotyped.<sup>41</sup> Following such simulated encounters, guided reflection regarding their attitudes, performance, and feelings can help students better understand the complex relationship between race, ethnicity, and language as well as how their assumptions or lived experiences inform their medical interactions or decision making.

Medical school curricula should account for the skills and needs of diverse learners—for example, Latinx students with Spanish language skills or cultural knowledge or experiences.<sup>42</sup> Institutional policies should address bilingual students' and clinicians' appropriate use of language skills, including clearly outlining qualifications and appropriate assessment methods and distinguishing the skills and roles of learners from those of medical interpreters.<sup>37</sup> These policies should protect untrained bilingual or bicultural students and staff from inappropriate requests to serve as **ad hoc interpreters**, a common workplace microaggression, thereby improving patient safety and quality of care for patients who speak non-English languages.

## Conclusions

A raciolinguistic perspective can inform how health care practices and medical education should be critically examined to support Latinx populations comprising heterogeneous communities and complex individuals with varying and intersecting cultural, social, linguistic, racial, ancestral, spiritual, and other characteristics. Future

studies should explore the outcomes of raciolinguistic reforms of health services and educational interventions across the health professions to ensure effectiveness in improving health care for Latinx patients.

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**Citation**

*AMA J Ethics.* 2022;24(4):E296-304.

**DOI**

10.1001/amajethics.2022.296.

**Conflict of Interest Disclosure**

Drs Ortega and Alemán report receiving royalties from Elsevier. The other authors had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**How Is Colonialism a Sociostructural Determinant of Health in Puerto Rico?**

José G. Pérez Ramos, PhD, MPH, Adriana Garriga-López, PhD, and Carlos E. Rodríguez-Díaz, PhD, MPH

**Abstract**

Puerto Rico is experiencing a public health crisis driven by effects and processes of US colonialism in the archipelago, such as the exclusionary application of federal health policy, an exodus of health care professionals, and the long-term effects of unequal distribution of health care funding in the unincorporated territories. Compound effects of multiple disasters, including Hurricane María, repeated earthquakes, and the COVID-19 pandemic, as well as relentless privatization and fragmentation of the health care system, have led to very poor health outcomes. Puerto Rico's case clearly shows the negative effects of colonialism on public health. This article specifies what decolonization requires from a public health standpoint to promote health equity.

**Public Health in Puerto Rico**

Puerto Rico has been experiencing a public health crisis since the 1990s, driven by limited resource allocation for preventive health care for residents of Puerto Rico, austerity policies in response to a massive debt crisis, and primary care privatization.<sup>1,2,3</sup> Compared to other jurisdictions in the United States, Puerto Rico has worse health outcomes, such as higher rates of preterm births, asthma, diabetes, cardiovascular disease, HIV/AIDS, gender-based violence, food insecurity, incarceration, and homelessness, among other outcomes.<sup>4,5</sup> Colonialism is literally killing Puerto Ricans.

It is well established that the health of communities is negatively affected by the social, political, and economic **impacts of colonialism**.<sup>6,7</sup> Some scholars have argued that colonialism is a social determinant of health, resulting in a state of forced dependency and lack of self-determination in the face of structural challenges that adversely affect living conditions.<sup>8,9</sup> Puerto Rico is an exemplary case in this regard, as its history demonstrates how social processes associated with colonialism—such as extractive economies, forms of unequal citizenship, and extreme labor exploitation that have formed part of both Spanish colonialism from 1493 to 1898 and US colonialism thereafter—have undermined public health as well as human and civil rights like education and disaster aid.<sup>10</sup> In particular, Puerto Rico's political subordination to US federal policy has led to the degradation of the public health care system through

measures such as chronic underfunding (for example, through its exclusion from the provisions of the Affordable Care Act) and through the fragmentation and privatization of local health care systems. Health inequities in Puerto Rico are rooted in forms of social inequality generated by colonial ideologies and institutions. As a result of Puerto Rico's lack of full political representation and self-determination (ie, US colonialism), public health in the archipelago is not equitable, nor is it generally responsive to the needs of the population it serves. We argue that US colonialism is the main sociostructural determinant of health in Puerto Rico.

### **Historical Injustice**

Puerto Rico's health care system was once exemplary. The regionalization of state health services in the 1960s increased access to care and quality of life for many.<sup>11</sup> The 1970s and 1980s saw an increasingly significant state retreat from social welfare policies, as also occurred in the United States at the time. From the early 1990s through the first decade of the 21st century, Puerto Rico's regional system of health care was replaced by one organized around notions of efficiency and the desirability of privatization as a way to improve services.<sup>1,3,12</sup> Privatization models have been implemented widely across socioeconomic infrastructures in Puerto Rico (eg, transportation, telecommunications, education, and energy), largely to detrimental effect.<sup>13,14,15,16</sup> The health care privatization model and subsequent efforts have functioned as a form of intensive value extraction for US corporations, as well as an opportunity for politicoeconomic assimilation to the United States for those whose ambition it is to see Puerto Rico become a US state by its mirroring US public health processes. Puerto Rican government efforts to facilitate political assimilation through public policy reform reflect colonial dynamics that induced Puerto Rican institutions to conform to US efficiency standards. Instead of a dignified and effective public system, health care in Puerto Rico has become a market commodity under the colonial regime of US health capitalism. These changes have aggravated health inequity in Puerto Rico, especially in marginalized and underresourced communities, and resulted in ineffective public health.<sup>9</sup>

Historically, political relations between the United States and Puerto Rico have not favored the archipelago. Public health imperialism has worked against Puerto Ricans, evidenced by well-known examples of discriminatory, racist,<sup>17,18</sup> and abusive approaches, including forced sterilization programs and Malthusian experiments with contraceptives between the 1930s and the 1970s,<sup>19</sup> radiation experiments on Puerto Ricans in the 1950s,<sup>20</sup> the testing of Agent Orange and other deforestation agents,<sup>21,22</sup> and attempts to test dubious insecticidal approaches during the 2015 Zika outbreak.<sup>23</sup> Notably, the US government's catastrophic disaster response to Hurricane María in 2017 led to an estimated 2975 excess deaths in the 6 months following the hurricane,<sup>17</sup> and it severely exacerbated preexisting health inequities.<sup>18,19,24,25</sup> Over time, many underserved communities have been disenfranchised, facilitating the continuation of exclusionary policies and putting lives at risk across generations.

Human-driven climate disruption leading to more frequent ecological catastrophes complicates this panorama, with an increasingly active cyclone season, larger and stronger storms, and significantly higher storm surges posing serious dangers to coastal communities.<sup>26</sup> For example, **Hurricane María**, which devastated Puerto Rico in 2017, was only 1 of 6 major hurricanes that year.<sup>27,28</sup> In addition, the eastern Caribbean region is very seismically active, with multiple earthquakes having occurred since December 2019 that have displaced hundreds of people. The spread of the SARS-COV-2 virus to

Puerto Rico in early 2020 placed additional stress on failing social infrastructure and health institutions already dealing with the effects of compounding disasters—post-hurricane pandemic life amidst ongoing earthquakes.<sup>29,30,31</sup>

### **False Promises**

Despite Puerto Rico's intended role as a Cold War "showcase for democracy"<sup>32,33,34</sup> and US-style capitalism, the archipelago's more than 120 years as a US territory have significantly contributed to the contemporary health crisis, which is characterized by hospital closures, a mass exodus of health professionals, poor health outcomes, and the imposition of fiscal austerity measures to curb public spending on health care and education.<sup>35</sup> In response to the large public debt, and given that Puerto Rico is excluded from bankruptcy protections under chapter 9 of the US Code of Federal Regulations, Congress authorized the 2016 Puerto Rico Oversight, Management, and Economic Stability Act (PROMESA),<sup>36</sup> which called for the creation of a Financial Oversight and Management Board (FOMB) for Puerto Rico to oversee Puerto Rico's finances. The FOMB, known colloquially in Puerto Rico as *La Junta*, has implemented austerity measures that favor large, US-based investors in highly speculative debt arrangements over public spending to support the population's health.<sup>18,19</sup>

PROMESA's austerity regime is one of the most deleterious aspects of contemporary US colonialism in Puerto Rico, compounding the impacts of natural disasters, such as earthquakes and hurricanes, as well as human-driven climate disruption. Combined with the effects of shipping restrictions contained in the Jones Act (enacted in 1920) and widespread corruption, austerity policies have led to the stripping of social assets (eg, government retirees' pension cuts, including health care insurance, which aggravate inequities in health care access)<sup>37</sup> and abandonment of the public sphere.<sup>38</sup> The effects of austerity on public health are palpable, including unmanaged mental health problems that can lead to interpersonal violence, as well as a high prevalence of diabetes and cardiovascular disease.<sup>12,39,40,41</sup> Residents of Puerto Rico—especially people with mental and physical disabilities, municipality island residents, rural residents, sexual and gender minorities, women, Afro-Puerto Ricans, Indigenous Puerto Ricans, and Dominicans and other migrants—struggle with a lack of dignified health care access.<sup>42</sup>

These austerity programs represent an imperialist form of governance that sacrifices and destroys the health of Puerto Ricans in favor of securing profit for wealthy investors. PROMESA's false promises reflect a long-standing reliance on the legal ambiguities and racialized inequalities enshrined in the congressional doctrine of unincorporation (ie, a permanent state of social, economic, and political limbo or a state of nothingness), which affects not only Puerto Rico but also the US Virgin Islands, the Mariana Islands, Guam, and American Samoa.<sup>43,44,45</sup>

### **COVID-19 Pandemic**

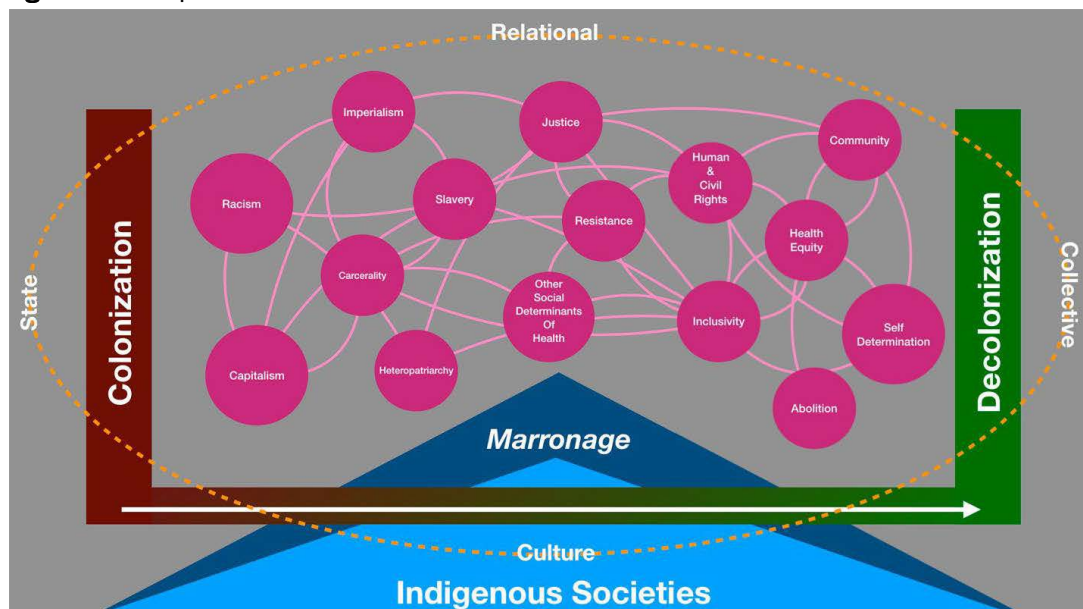
PROMESA-driven measures have also left Puerto Rico in a precarious position with regard to managing the COVID-19 pandemic by increasing preexisting health risks and exacerbating health inequity.<sup>38</sup> In addition, Puerto Rico has faced several challenges in combatting the pandemic, including having to compete against states to secure protective gear, test kits, and vaccines during a time when the federal government was unconcerned with the impact of the pandemic on the jurisdiction.<sup>46</sup> The structural inequities and racist, colonial discrimination against communities in Puerto Rico by the US government represent a serious risk to the population in future public health emergencies.

## Decolonization

Public health infrastructure in Puerto Rico has significantly worsened because of socioeconomic and political decisions and the passage of PROMESA, which exacerbated health inequities in the archipelago.<sup>47</sup> However, public health governance could be improved through the application of a reparative social justice model and international human rights frameworks and standards. Furthermore, one way decolonization could be pursued would be through the reinstatement of Puerto Rico on the United Nations' list of non-self-governing territories in need of decolonization.<sup>48</sup> Such an effort could support Puerto Rico's self-determination and political autonomy through internationally recognized decolonizing mechanisms (eg, independence or free association as an independent state).<sup>48,49</sup>

How can this harmful situation be resolved in the service of enhanced public health and increased social power? As our diagram shows (see Figure), colonization is embedded in every aspect of society and represents a constant force generating oppressive conditions for colonized peoples and places. Yet decolonization as a sociocultural process and practice has always been present in resistance to colonialism and slavery. And it continues to this day, particularly as a social, economic, and cultural process.<sup>28,49,50</sup> Although decolonization is certainly complicated, it is nonetheless necessary and arguably inevitable as a collective process of democratization.

**Figure.** The Impact of Colonialism as a Sociostructural Determinant of Health



Colonialism is the most significant sociostructural determinant of health and the root of health inequities in Puerto Rico. Colonialism precludes the fundamental right to self-determination and offends the dignity of the colonized, which affects public health and well-being. The unethical nature of *La Junta* in Puerto Rico reflects the fundamentally undemocratic nature of US colonial power in the archipelago. The remedy for colonialism is reparations and a process of self-determination, which are necessary for the full enjoyment of human rights, including the right to health.

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#### Citation

*AMA J Ethics.* 2022;24(4):E305-312.

#### DOI

10.1001/amajethics.2022.305.

#### Conflict of Interest Disclosure

Dr Diaz reported receiving research funding from the National Institutes of Health, Gilead Sciences, and AbbVie, as well as funding to collaborate with the Centers for Disease Control and Prevention on the implementation of interventions. Drs Pérez Ramos and Garriga-López had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*





## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E313-318

### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### Language and Health (In)Equity in US Latinx Communities

Zackary Berger, MD, PhD and Yael Peled, DPhil

##### Abstract

Language is a social determinant of health, no less so in the case of Latinx persons, who make up the second largest ethnic group in the United States. In US health care, language and linguistic difference are often conceived in discrete, instrumental, and monolithic terms. This article characterizes this conception of language as administrative logic, which is in sharp contrast to language conceived as a richly complex, heterogeneous, communally lived human experience. This article emphasizes the importance of system-level language awareness and epistemic humility for promoting equity, as well as the need to avoid too-narrow focus on linguistic assessment.

##### Administrative Logic

Many residents of the United States, including health care workers, are aware that Latinx make up the second largest ethnic/racial minority group in the United States. Less often realized is the heterogeneity that underlies this classification.<sup>1</sup> (We use the label *Latinx* throughout primarily for reasons of thematic and conceptual coherence with the rest of the contributions in the thematic issue, while recognizing the social significance and political salience of relevant competing or interrelated notions, such as *Latinidad* and *Indigenidad*.) In what follows, we outline the implications of the sociolinguistic context of US Latinx for their clinical care. More specifically, we consider the ways in which the quality and equity of care provided to US Latinx are affected by a profound tension between the Anglo-centric and often monolingual administrative logic of health care institutions, on the one hand, and the complexities of Latinx' linguistic lived experience of health and illness, on the other. More specifically, we offer a critique of this administrative logic in the context of health care, and we examine how a less regulative-centered conception of language and linguistic agency can better serve health care policies and practices committed to equality, diversity, and inclusion and likewise guide their development, implementation, and assessment.

##### Heterogeneity in Latinx Linguistic Identities

The goal of equitable health care delivery to US Latinx—and to other US demographic groups—has a critical linguistic dimension. Most studies show that linguistically concordant care improves health outcomes.<sup>2,3</sup> Linguistically discordant care often leads to patient dissatisfaction, lower quality of care, inappropriate follow-up, and worse health outcomes.<sup>4,5</sup> That is, care in a language other than that preferred by the patient

can “expose” poorer quality care and lead to deleterious or disparate outcomes. These findings, however, do not imply that addressing this discordance necessarily entails slotting any and all Latinx patients into the Spanish language administrative rubric. Not all Latinx speak Spanish as their first or primary language or even speak it at all (eg, Indigenous migrants, whose experience of the immigration system involves similar discordance).<sup>6</sup> Even those who do speak Spanish may not speak the specific variety of the language assumed by the institution. This state of affairs further compounds the extent of linguistic disadvantage experienced by Latinx individuals seeking care.

To take another example, the perceived ubiquity of Spanish—a spoken language—can also marginalize Deaf and hard-of-hearing Latinx, who face, alongside the numerous socioeconomic and psychosocial factors involved in acculturation, “additional factors unique to their situation, such as community attitudes about disability, multilingualism (some people have to navigate up to four languages), multicultural values, exposure to multiracial communities, limited availability of mediators (Deaf individuals of their own country), and family issues.”<sup>7</sup> Their linguistic repertoires will necessarily be reflective of their individual linguistic histories and experiences with regard to, for example, access to sign language in country of origin, the specific sign language(s) of that country, opportunities to acquire multimodality and multilingualism in signed and spoken languages, and so on.<sup>7</sup> These complex linguistic identities—and the divergent communicative preferences and needs that arise from them—highlight the factual error (and practical inadequacy) of equating Latinx with Spanish speaking.

### **Monolingual Ideology as a Source of Harm**

The underlying multidimensional sociolinguistic diversity of US Latinx can serve as entrée to a linguistic state of affairs often overlooked by busy clinicians, overwhelmed patients, and harried administrators, many of whom are rarely trained specifically in navigating multilingual and multimodal realities arising from linguistic difference. US hospitals and health care systems are commonly constructed on a presupposition of a monolingual linguistic culture, dominated by the unrivaled power of English. Such administrative logic, particularly when coupled with monetary incentives geared towards serving well-off patients, means that the complex linguistic heterogeneity of US Latinx is very rarely recognized in the clinical setting.

Such administrative logic cannot be understood as purely instrumental and value neutral, however. Rather, it is rooted in a distinct ideology in which language is viewed as an autonomous entity used for conveying information.<sup>8</sup> Linguistic difference is thus conceived as a problem, reflected in its being labeled as a barrier, because such difference introduces potential errors in information transmission and resulting inefficiencies.<sup>8</sup> These beliefs constitute a type of linguistic ideology according to which the perceived problem of language needs to be solved through intervention, a view that is often linked to the social and cultural subordination of the less linguistically powerful.<sup>8</sup> This orientation affects the care of linguistically heterogeneous Latinx in the United States in envisaging language difference primarily as a problem that requires a solution, but it is far less concerned with the power relations that define the parameters of the problem or the terms of its proposed solutions.

### **Linguistic Difference in Health Communications**

Linguistic discordance is not merely affected by linguistic difference in the narrow sense of the difference between language A and language B. Even when both languages are understood in more inclusive terms (eg, not restricted to standardized, high-resource

spoken varieties), the existence of a language barrier is further compounded by additional layers of critical difference. For example, there is a (perceived) gap in epistemic authority and credibility between the globally powerful languages of science and technology that dominate contemporary transnational knowledge development and production and less powerful languages in which conceptions of health, illness, and well-being are grounded in local and traditional knowledge systems.

There are also other layers of linguistic difference. Linguistic differences might arise in the care of individuals with complex communication needs (eg, various communication disorders). Still another vitally important layer pertains to the difference between habitual language and disrupted linguistic agency (eg, the profound experience of “indescribability” in depression<sup>9</sup>). In another example, the complex linguistic response to trauma, in terms of both experience and narration, may drastically affect a person’s habitual interaction with linguistic interlocutors, as manifested in “his or her inclination to learn languages, to use, retain, or abandon a particular language, or to take refuge in silence.”<sup>10</sup> Health care practitioners—and institutions more broadly—should not lose sight of these additional layers in planning and evaluating the care they provide to linguistic minorities.

The inadequacy of slotting Latinx patients into neat language boxes, or the tendency to see language only as a barrier rather than as intrinsically linked to individual and societal complexity, is even more relevant in the current Covid-associated syndemic.<sup>11</sup> In the context of the clinical experience of the first author (Z.B.), a common assumption of administrative logic is that merely replacing English with Spanish is enough to fully meet the communicative needs of Latinx during the Covid-19 pandemic, an assumption that, in addition to overlooking Latinx’ linguistic heterogeneity, fails to acknowledge the intersection of economic, social, political, and juridical constraints on this community.

### **Cultivating Linguistic Humility**

These considerations illustrate just how complex and multifaceted health communication is even in supposedly **linguistically concordant settings**, let alone in their discordant counterparts. They also emphasize the need to keep in mind that interpretation—even in best-case scenarios when it is available, funded, and certified—is better envisaged not as a fix to communicative barriers but rather as a tool that needs to be properly utilized and whose benefits as well limitations need to be understood.<sup>12</sup> The awareness that interpreters are not merely language conduits between language A and language B and the need to reconcile and calibrate the different perceptions of all parties involved in interpreted health communication<sup>13</sup> constitutes another important insight into the crucial shortcoming of an uncritical conception of language (eg, discrete, instrumental, disembodied) that often underlies the administrative logic of health care institutions.

It is pivotal to highlight that an uncritical conception of language is not merely a theoretical or intellectual preoccupation. Rather, it has a clear and immediate effect on the efficient utilization of various resources and services provided with the aim of delivering equal care to patients of all linguistic profiles and identities. Concerns about the cost of such services (eg, translation and interpretation, cultural liaison, and patient navigator capacities), given real-world resource limitations, rarely address the problem of their **inefficient utilization** by clinicians and administrators due to lack of sufficient language awareness. For example, an administrator might incorrectly infer on the basis of minimal input (eg, a greeting, asking directions) that a patient in fact speaks English

and therefore dismisses the interpreter. Or a clinician might request sign language interpretation to communicate with a Deaf patient without being aware that there exists more than a single sign language and that different sign languages are not necessarily any more mutually intelligible than different spoken languages are. We thus suggest that cost-related concerns over linguistic accessibility in health care ought to be considered—and perhaps also reevaluated—in relation to the question of whether or not health care institutions are in fact sufficiently language aware to adequately utilize the existing range of resources<sup>14</sup> and how to assess ongoing and future needs.

Relatedly, we also wish to emphasize that attempts to “fix the (interpretation) fix” on the part of practitioners with some competency in the patient’s language, by cutting out the (communicative) middleman altogether, should be regarded with caution. Such shortcuts incur the risk of false fluency and the encouragement of an institutional linguistic culture of “getting by” at the expense of certified interpretation.<sup>15</sup> This tendency is reinforced by the expectation on the part of some academic medical centers that in-person interpretation is a dispensable luxury, completely replaceable by video or audio equivalents.

Our point is not to completely discourage practitioners from using their linguistic competency in such encounters. Indeed, we are mindful of the risk that an institutional linguistic culture centered on formal assessment and credentials might result in appropriating language from noncertified bilingual practitioners and minimizing the contribution of domestic speakers of the language.<sup>8</sup> Rather, we seek to highlight the importance of clinicians developing a sense of linguistic epistemic humility based on “an attitude of awareness ... of their own linguistic epistemic capacities ... the recognition of their limitations, and the active search for sources outside one’s own linguistic epistemic capacities to help overcome them.”<sup>16</sup> In the context of health care provision for US Latinx, linguistic **epistemic humility** entails not simply an honest self-assessment of one’s Spanish competency, but also the capacity to assess the degree of relevance of Spanish to begin with, given the linguistic heterogeneity among Latinx patients, as described above.

### Conclusion

Making health care institutions more linguistically inclusive for Latinx patients entails challenging a monolingual and Anglo-centric administrative logic. However, doing so requires more than simply equating Latinx with Spanish speaking. A better-informed understanding of the spoken and signed linguistic heterogeneity of US Latinx is fundamental for a more equitable health care delivery committed to patients’ equal linguistic dignity. Power often gives rise to an unexamined assumption of sufficient knowledge,<sup>17</sup> whose presence can be detected in the linguistic ideologies that underlie the administrative logic of present-day health care systems and institutions. Challenging the assumption of sufficient knowledge by pursuing enhanced linguistic understanding can therefore contribute significantly to addressing present-day US Latinx health inequities.

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**Citation**

*AMA J Ethics.* 2022;24(4):E313-318.

**DOI**

10.1001/amajethics.2022.313.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**How Should Representation of Subjects With LEP Become More Equitable in Clinical Trials?**

Jonathan Alhalel, Nicolás Francone, Sharon Post, Catherine A. O'Brian, PhD, and Melissa A. Simon, MD, MPH

**Abstract**

Underrepresentation of individuals with limited English proficiency (LEP) who speak Spanish is ongoing in phase 3 biomedical clinical trials and exacerbates health inequity. This article suggests strategies for increasing representation of Spanish speakers in clinical trials by emphasizing the importance of early engagement with Spanish language communities, inclusive participant recruitment, and collaborative trial design and implementation. Although investigators and institutions administering government-funded research must meet federal requirements for language assistance, journal editors, peer reviewers, institutional review board members, academic health centers, and all beneficiaries of the biomedical and behavioral research enterprise in the United States must motivate linguistic inclusion.

**Underrepresentation Exacerbates Inequity**

Hispanics with limited English proficiency (LEP) are underrepresented in clinical trials for health care interventions that can improve health outcomes, which limits the generalizability of the findings.<sup>1,2,3,4,5</sup> Underrepresentation of Spanish speakers in research limits subgroup analyses to determine whether treatments are effective for this population, which exacerbates health inequity,<sup>6</sup> especially in type 2 diabetes care in the United States.<sup>7</sup> By *underrepresented*, we mean that participation of individuals from racial, ethnic, or linguistic groups is not proportional to their share of the population meant to benefit from trial findings. For instance, in adult vaccine trials reporting racial/ethnic participation data, Hispanics composed 11.6% of trial participants (as low as 3% in cancer clinical trials),<sup>6</sup> although they constituted 18.5% of the US adult population in 2019.<sup>3</sup> Notably, only 54% of cancer trials and 34% of vaccine trials reported ethnicity, limiting understanding of health disparities in those studies.<sup>3,8</sup>

For Spanish-speaking Hispanics in particular, limited access to culturally and linguistically appropriate services (CLAS) is a barrier to accessing health care and participating in clinical trials, despite federal law recognizing the legal right to CLAS for individuals with LEP.<sup>9,10</sup> Ideally, meaningful inclusion in clinical trials would go beyond numerical representation and include powering studies to detect differences between

racial, ethnic, and linguistic groups with respect to the effectiveness of new interventions and to identify health inequities and barriers to care that are unique to these groups. Failure to meet this standard of inclusivity for Spanish-speaking participants in clinical trials perpetuates health care inequities and limits physicians' ability to provide the most effective treatments for all patients. For example, a study of the accuracy of depression-screening instruments that were developed in trials that typically excluded non-English speakers found that ultrashort screening instruments might be inaccurate when used with Spanish-speaking populations.<sup>11</sup> Therefore, physicians, researchers, and funders must embrace a broader ethical obligation to expand language access and inclusive participation during clinical trial recruitment and throughout the research pipeline. Given that Hispanics are the largest—and a growing—minority group with LEP in the United States and are often language discordant with health care professionals, their unique situation needs to be explored and discussed.<sup>12,13,14</sup>

### **Excluding Non-English Speakers From Clinical Research**

Proposed explanations for low recruitment of Black, Indigenous, and people of color (BIPOC) in research include concerns about safety and exploitation based on past and present racism, discrimination and ill-treatment within the health care system, BIPOC's unfamiliarity with research, and the effect of socioeconomic factors on participants' ability to devote time to a clinical trial.<sup>15</sup> In the case of Spanish-speaking participants, commonly stated reasons for exclusion include researchers' inadequate preparation and the need to adapt study measurement tools for Spanish-speaking participants and to recruit bilingual staff.<sup>1</sup>

These reasons do not reflect immutable characteristics of Spanish speakers themselves, nor can they be explained merely by gaps in technical capacity to ensure language access in clinical research. Rather, underrepresentation of Spanish speakers in clinical trials reflects exclusionary practices (eg, English fluency requirements) that can be reversed by prioritizing inclusion in study design and engaging Spanish-speaking communities in the earliest stages of clinical research. Nevertheless, exclusion of individuals with LEP in clinical trials may be on the rise. The proportion of emergency medicine journal research articles excluding non-English speaking (NES) individuals increased from 6.4% in 2004 to 16.2% in 2014, and 42% of articles failed to mention whether NES individuals were included in or excluded from the research.<sup>16</sup> Without the expectation to report or explain the exclusion of non-English speakers from studies, there is no accountability for inclusivity, leading to research designs that exclude individuals with LEP from the onset. The exclusion and lack of reporting reflects a lack of will to shift research culture toward equity and inclusion.

### **Role of Language Discordance**

A 2013 Pew Research analysis showed that 32% of Hispanics ages 5 and older speak English less than “very well” or “not at all,”<sup>17</sup> yet there is little research on the use of Spanish in recruiting patients for clinical trials.<sup>18</sup> Adding a dedicated enrollment phone line in Spanish increased the representation of Hispanics in one study from 14% to 24%,<sup>19</sup> and the quality and quantity of physician-patient communication in the clinical setting has been shown to affect patients' decision making for clinical trial enrollment.<sup>20</sup> These findings suggest that having Spanish-speaking research staff can improve clinical trial enrollment of Hispanics with LEP.



Legal requirements for language assistance and mandates for proportional racial and ethnic representation in federally funded research have proven unsuccessful in changing **exclusionary research designs**.<sup>21</sup> Studies show that interpreters are underutilized in medical settings despite legal requirements but document improvements in patient outcomes when professional interpreter services are used with LEP populations.<sup>22,23</sup> There is little reason to believe that interpreters are widely available for clinical trials, for which less federal guidance on access to language assistance and less knowledge of the benefits of such access exists.<sup>24</sup> The underuse of **Spanish interpreters in health care**, together with the common practice of explicitly excluding non-English speakers from trial recruitment and inconsistent reporting of racial and ethnic representation in study populations, reflects structural racism that systematically neglects the basic requirement for Spanish-speaking individuals to share equitably in the benefits of clinical research.

The connection between underrepresentation in clinical trials and worse health outcomes among Hispanic persons with LEP is strongly suggested by the worse health outcomes Hispanic persons experience with respect to diabetes. Hispanic patients in the United States were twice as likely to be hospitalized for treatment of end-stage renal disease related to diabetes in 2017 compared to non-Hispanic White patients and 1.3 times more likely than non-Hispanic White patients to die from diabetes in 2018.<sup>25</sup> A systemic review of 14 367 clinical trials registered on ClinicalTrials.gov between 1 January 2019 and 1 December 2020 with English language proficiency as an inclusion criterion found that 19% required trial participants to be able to read, speak, and/or understand English.<sup>6</sup> Furthermore, examination of the subset of 85 diabetes trials showed that 29% required English language proficiency and hence excluded Hispanic persons with LEP, and only 9% specified Spanish language accommodation.<sup>6</sup> The principles of justice and respect demand equity in clinical trial participation with no exception for any discriminatory practices.

It is important to note a counterargument rooted in the principle of beneficence. Language assistance services in clinical trials add to costs that may reduce the number of potentially beneficial trials conducted, thereby depriving many of those potential benefits. However, given that language access in health care has been recognized by US law as a civil right<sup>10</sup> and that there is evidence of harm to individuals with LEP from underrepresentation in clinical trials, we posit that proper representation of such individuals in clinical trials has greater potential for maximizing benefits and minimizing harms than the alternative of exclusion.

### **A Language Justice Approach**

The idea of distributive justice—the fair distribution of scarce resources—begets an ethical and moral imperative to embed inclusive practices, such as language assistance, in clinical trials.<sup>26</sup> A language justice perspective takes linguistic diversity as its starting point, valuing the autonomy and self-respect of linguistically diverse individuals and identifying an ethical demand for health care and research institutions to create inclusive, multilingual spaces that facilitate participation and the equitable distribution of the benefits they produce.<sup>27</sup> While the focus of this paper is on the Hispanic population in the United States, we assert that there is likewise a need for inclusiveness across other language barriers, such as those encountered by Asian (eg, Chinese, Vietnamese) populations, to achieve equity in clinical trial access. We posit that cost and other barriers to inclusivity can be mitigated as artificial intelligence technologies

advance and make translation of forms, recruitment materials, and other resources more readily available.

### Recommendations

A restructuring of clinical trials is fundamental to create inclusive, multilingual spaces, and opportunities exist to make valuable, long-lasting changes. These opportunities include requiring every study protocol to include consideration of and goals for linguistic groups, investment and planning to ensure that adequate language resources are available to properly educate patients on their options, and clear protections for individuals with LEP during the informed consent process and continuously after study enrollment. Fulfilling the ethical demands for inclusive clinical trials also requires research funders to prioritize language access by including expenses for language assistance resources in all clinical trial budgets.

As gatekeepers to publication, journal editors and reviewers can set more stringent standards for inclusive clinical trials, thereby encouraging inclusive recruiting if researchers wish to share their findings with the scientific community. Strategies can include guidelines for authors and reviewers on inclusive submission requirements and sample language to explain the reasoning behind paper rejection if authors do not include or explain representation of specific populations in their studies.<sup>28</sup> Physicians can also play a role in inclusivity by actively prioritizing language access in clinical practice and creating the expectation for linguistic inclusiveness in research.

### Conclusion

Much work is needed to overcome the inequities Hispanics face in clinical trial enrollment. More specifically, Hispanics with LEP have worse health outcomes and are often excluded in clinical trials simply because of the language they speak, leaving them underrepresented. The current exclusion leaves a large window of opportunity for health equity and improved quality of life for individuals with LEP. To truly advance racial and ethnic representation in research and especially clinical trials, we should all strive to work together for linguistic inclusiveness as a goal.

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**Citation**

*AMA J Ethics.* 2022;24(4):E319-325.

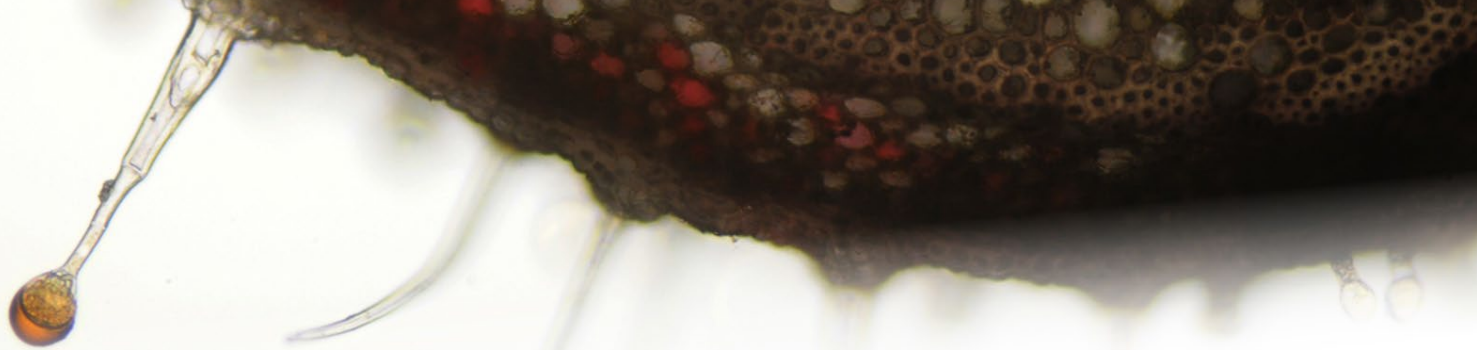
**DOI**

10.1001/amajethics.2022.319.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E326-332

### HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

#### Why Restoring Birth as Ceremony Can Promote Health Equity

Marinah V. Farrell

##### Abstract

Until the mid-20th century, birth in the United States for Latinx Indigenous peoples was an ancestral ceremony guided by midwives and traditional healers (*parteras curanderas*). As American physicians and nurses increasingly differentiated themselves from traditional midwives, midwives of color in particular were disparaged and excluded from helping women give birth and thus from making birth a cultural foothold in their lives. As a result, communities of Latinx Indigenous peoples were culturally and spiritually separated—via the marginalization of *parteras*—from important health traditions, which caused suffering and illness. Reimplementation of birth as ceremony means babies can be born (and communities reborn) into an ancestral cultural ecology characterized by safety and cultural reclamation of healing.

*Birth informs much of what scholars refer to as Mexican traditional medicine. It is a foundational paradigm of regeneration.... One way to understand birth as ceremony is to view the body as a container not only for the spirit, but also for principles of nature and life. Native people call these guiding principles “natural laws.”*

Patrisia Gonzales<sup>1</sup>

##### Marginalization of Community Midwifery

Until the mid-20th century, birth in the United States for Latinx and Indigenous peoples was an ancestral ceremony in which midwives and traditional healers (*parteras curanderas*) provided physical and spiritual care. Despite the immense challenges of working as a midwife in rural or poor communities, midwives saved lives and were beloved primary caregivers in traditional communities. Midwives not only attended births and provided prenatal and postpartum care, but also gave guidance on breastfeeding and on healing remedies for most reproductive ailments, worked with family physicians or obstetricians on serious cases, provided abortion care, and were even consulted for ordinary colds and injuries. Additionally, in many Indigenous communities, midwives were also seen as being able to cure spiritual illnesses (and consequently persecuted by religious inquisitors in the Americas), which contributed to community rituals honoring life passages, such as births, deaths, puberty, menstruation, and menopause. In Mexico, midwives are still considered “the inheritors of the prehispanic female doctor, the speakers for the goddess, the priestesses of life, [and] the protectors of health.”<sup>1</sup> At one time, within certain established systems of health care in the Americas (although not in

the United States), midwives were even considered on par professionally with physicians.<sup>2</sup>

In the 1930s and 1940s, US obstetricians increasingly differentiated themselves from traditional midwives by enacting standardized medical school curricula, formal credentials for practice, and professional societies with the authority for self-regulation, all with a focus on the pathology of “dangerous” childbirth.<sup>3</sup> This marginalization of traditional and fundamental healers (such as *parteras*) has separated Latinx Indigenous communities from their cultural and spiritual health. Indigenous midwifery is based on communal, spiritual, and bodily knowledge, and birth is viewed as a **natural** part of the life cycle as opposed to the scientifically or medically sanctioned model of birth that generations of Indigenous communities had forced upon them.<sup>1</sup>

### ***La Partera Curandera***

In the 1930s, although not legally recognized with licensure in North America, traditional *parteras* were actively working in underserved communities in the United States. In New Mexico’s San Miguel County, *parteras* attended 72% of all births in 1936.<sup>4</sup> One midwife in the region, Jesusita Aragon, attended 12 000 births in her lifetime in the region of Las Vegas, New Mexico, as one of the last remaining traditional midwives in New Mexico.<sup>5</sup> Yet, at the turn of the 20th century, midwives had begun to be marginalized as newly professionalized doctors, with the support of their middle- and upper-class patients, encouraged hospital delivery to ensure the safety of mother and child.<sup>6</sup> Slowly, the communal and intimate nature of midwife-attended births, wherein only the most difficult deliveries were attended by physicians, became medicalized, thereby merging “ordinary” and “emergency” practices.<sup>7</sup> As Laurel Ullrich notes, this trend “demanded the elimination or further subordination of social healers. To allow a woman to continue to practice midwifery, or, by extension, any other form of independent healing, deprived male doctors of the experience they needed and at the same time perpetuated the notion that un-educated people could safely care for the sick.”<sup>7</sup>

This narrative of Indigenous-based medicine as unsafe, unscientific, and unhygienic meant that midwives would continue to care for families in communities that were not being served due to rural geography, racism, or poverty. Traditional midwives were blamed for poor outcomes and no longer seen as healers but instead as old, illiterate midwives of color with suspicious cultural practices.<sup>8</sup> Traditional White midwives serving poor communities (such as Appalachian midwives) were considered similarly bereft of education but cast as heroes worthy of support or (if economically resourced) trained as obstetric nurses under the watchful eye of the medical system.<sup>9</sup> Physicians of the time referred to the “midwife problem” of poor midwives of color who needed to be eliminated or reformed via supervised nursing.<sup>10</sup>

### **Elimination of US Midwifery**

Between 1945 and 1965, the number of *parteras* in New Mexico fell from 800 to under 100, a decline that was accelerated by New Mexico’s implementing regulations in 1979 that required midwives to have formal education and pass a written licensing exam.<sup>4</sup> In the United States, more and more states began to convict midwives or demand that they be licensed regardless of experience or years as a birth attendant, and, for many *parteras*, licensing was not accessible due to financial, geographic, literacy, or educational barriers.<sup>11</sup> Even in areas such as Puerto Rico, where Latinx midwives were registered, midwives disappeared entirely by 1970.<sup>12</sup>

By the mid-20th century, the diverse ways in which Latinx and Indigenous communities honored birth and death in the hands of traditional healers—with traditional medicines and ceremony and forgoing interventions in a hospital setting—were deemed dangerous and irresponsible by policymakers favoring medicalized, profit-making health systems.<sup>8</sup> Communities of color were assimilated into the health care system, but their *parteras* were replaced with obstetrical nurses. Women were birthing in hospitals that reflected neither their cultural customs nor community members and were often far from home. As a result, people of color and the poor were denied their culture of health shared with *parteras* and for decades faced mistreatment in the hospital, separation from community, and medical interventions, such as sterilization, done without consent.<sup>13,14</sup>

This cultural and social elimination of midwifery was accompanied by the **medicalization of childbirth** by White men who viewed the bodies of pregnant women of color as “things in need of regulation ... because it subconsciously allows for the perpetuation of race, gender, and class hierarchies and structures.”<sup>8</sup> Moreover, as Danielle Thompson notes:

[T]he scholarship and data ... show us that these stereotypes have had startling, statistically significant, and systematic effects on pregnant women and mothers of color.... Increased control of pregnant and reproductive-age women of color paralleled and directly intersected with midwifery regulation by using seemingly scientifically and socially necessary measures such as eugenics-based anti-miscegenation laws as well as birth reporting laws.<sup>8</sup>

Viewed as uneducated, inferior practitioners, *parteras* that did continue to practice lacked support from local health care systems. Legal recognition could have helped midwives and their patients by generating formal education opportunities and financial resources to counter maternal and newborn mortality, particularly in Indigenous and Black communities, and especially in communities with neither physicians nor health centers.<sup>11</sup> In Mexico, midwives were used as scapegoats for poor outcomes by physicians or local officials.<sup>15</sup>

Much was and is broken in how the Latinx community attends to birth and the postpartum period. Ironically, as the Latinx community acculturates, its propensity for good health declines despite greater health care use in a process known as the Hispanic paradox.<sup>16</sup> Some of the most significant negative impacts of US acculturation can be seen in reproductive and newborn health. Studies have found that as Latinx peoples become more acculturated, their rates of infant mortality, low birthweight, and prematurity increase significantly, and they are more likely to have unhealthy behaviors before birth and after birth, including decreased breast feeding.<sup>16</sup>

### **Restoring Cultural Healing Practices**

There has been little success in honoring the traditional roots of Latinx healing at a systemic level since the Americas established male-centric European models of institutionalized health care. According to Mitchell Kaplan and Antonio Zavaleta: “The importance of Latino cultural beliefs in health care and our failure to fully understand or incorporate them into the clinic setting, and our general lack of attention to culture, has greatly impaired our ability to deliver appropriate health care to the Latino population in America.”<sup>17</sup> Within the current US hospital system, the most sacred Latinx traditions concerning reproduction, birth, and the critical nurturing care of parent and newborn are generally absent, particularly for immigrant families separated from one another and their supportive cultural and ceremonial traditions by border politics and economic realities.



Although colonizers and institutions eliminated the tradition of community birth, which is absent in the recent memories of our elders, ceremonial ways of birthing can be rewoven. Patrisia Gonzales describes the *promotora-investigadora*, wherein the validation of healing knowledge is integral or “cellular” to Mixteco and Indigenous peoples even with this enforced disconnection from birthing ceremonies.<sup>1</sup> A culture of healing can be found instinctually regardless of the geography of the Latinx diaspora and regardless of whether one is displaced as an immigrant in another country or is rooted in one’s ancestral village: “through stories, symbols, acts, and events, people create ways to frame their knowledge and assert their self-authored ways of being and knowing. They help to create the ‘therapeutic landscape’ and the evocative power of place on health.”<sup>1</sup> Cellular healing is there when we recall our *abuelita’s* *medicinas* or when we sit by a *governadora* bush after a desert rain. Ceremony is in taking manzanilla tea for comfort or a bath wherein a matriarch washes spiritual illnesses down the drain and a midwife buries the placenta deep in the sacred earth for the baby’s lifelong protection and connection to the land.

Another way of recreating ceremonial birthing is through encoded knowledge, which encompasses the quiet healing ceremonies of communities as part of survival and is embedded in symbols and codes. This encoded knowledge has survived largely because women healers and ancestors have guarded the knowledge for future generations.<sup>18</sup> We carry the sacred healing within as borders are crossed, poverty and discrimination are endured, and machismo and inaccessible health care endanger the lives of our mothers and newborns. Perhaps this ancestral endurance contributes to another Hispanic paradox, whereby US Latinx peoples have a longer average life expectancy than non-Hispanic White people.<sup>18</sup>

Encoded knowledge of Latinx and Indigenous communities is genetically inaccessible to outside researchers and data miners whose research often yields mythical farce, incomplete data, or the academic narrative of an outsider unable to center Latinx epistemologies. There is a true need to decolonize research, such that the underlying assumption that mainstream medical methods are objective would be seriously challenged.<sup>19</sup>

A community, all its relationships and lifeways, can splinter when foundational healers are deemed irrelevant. It was not so long ago that the *parteras* and other medicine peoples were considered gifted by the Creator, connecting those in the community to the healing of their ancestors, to their ecosystem, to their traditional foods, and to themselves. If we imagine the return of birth as ceremony, as the basis of our ancestral healing ways, babies would be born into an ecosystem of cultural safety. Although so much precolonial history of birth has been erased, forgotten, and destroyed by the colonizers, I believe the ancestors whisper: “Our culture heals us.”

### **Re-Indigenous Birth in the Americas**

Grassroots revival of traditional birth work is taking place all throughout the Americas, with many traditional birth workers wanting the integration of ancestral medicine to be respected within their professional licensure. In Canada, midwifery laws have started to include an expanded scope of practice for First Nations midwives in that country,<sup>20</sup> inspiring those of us in the United States to consider what innovative regulations can be worked on for midwives serving Indigenous communities. The root causes of maternal mortality are often a lack of access to care and to caregivers grounded in cultural understanding, as well as a lack of reproductive health care practitioners overall in the

United States. The United Nations Population Fund report, “The State of the World’s Midwifery 2021,” makes it clear that, if given the supportive infrastructure, midwives are the solution to counter the high rates of maternal mortality and morbidity in communities of Black, Indigenous and people of color (BIPOC).<sup>21</sup>

The revitalization of birth as ceremony is a way to recover the humanity of one’s indigeneity, the connection we as Latinx peoples have to the natural world and to community health. As Latinx communities became “deceremonialized,” they became separated from culture, kinship, ceremony, story, narrative, art, music, and means of education.<sup>22</sup> In the last 2 decades, BIPOC-led organizations with a focus on reproductive justice, data sovereignty, and reclaiming health as a human right have been growing in number. Many are working exclusively on policy to provide access to midwives for Indigenous communities by opening Indigenous-led birth centers and midwifery practices, creating community-based certification programs and educational opportunities for Indigenous students, and supporting medical practitioners who wish to use traditional medicine and ceremony in hospitals or health care settings.<sup>23,24,25,26,27,28,28,30,31</sup> As the only Indigenous midwife in my state when I was licensed in 2003 (indeed, the only midwife of color), I am now part of many well-funded coalitions and groups dedicated to Indigenous healing in reproductive health across the United States. To bring ceremony back to birth is the radical process of rehumanization and connection to the divine. It is also a radical reimagining of what culturally based and sovereign systems of reproductive health care and data collection would look like when created by and for Indigenous communities. L. T. Smith writes:

[T]here is a point in the politics of decolonization where leaps of imagination are able to connect the disparate, fragmented pieces of a puzzle, ones that have different shadings, different shapes, and different images within them, and say that ‘these pieces belong together.’ The imagination allows us to strive for goals that transcend material, empirical realities. For colonized peoples this is important because the cycle of colonialism is just that, a cycle with no end point, no emancipation. The material locates us within a world of dehumanizing tendencies, one that is constantly reflected back on us. To imagine a different world is to imagine us as a different people in the world. To imagine is to believe in different possibilities, ones that we can create.... Decolonization must offer a language of possibility, a way out of colonialism.<sup>19</sup>

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#### Citation

*AMA J Ethics.* 2022;24(4):E326-332.

#### DOI

10.1001/amajethics.2022.326.

#### Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



# AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E333-339

## PERSONAL NARRATIVE

### Why Community Health Workers' Roles in Latinx Communities Are Essential

Wandy D. Hernandez-Gordon, CD(DONA), BDT(DONA), CLC, CCE(ACBE)

#### Abstract

This first-person narrative examines life-changing effects that community health workers (CHWs) have on the well-being of marginalized community members and illuminates Chicago, Illinois' HealthConnect One as an example of a new health care organization needed to promote equity. CHWs offer culturally informed health services that are healing and transformative, and their work promotes health practice reforms that motivate equity through incremental and steady change. CHWs' work also underscores the need for clinicians and organizations to respond to deeply entrenched, long-standing patterns of oppression in ways that draw upon data and lived experience to support and advance linguistically and culturally proficient service delivery in Latinx communities and in all marginalized communities.

#### Need for New Health Service Delivery Models

In January 2021, we faced the unfathomable knowledge that every 26 seconds, someone was dying from COVID in America.<sup>1</sup> Yet Latino and Black Americans and American Indian/Alaska Natives have COVID-19 death rates at least 2 times higher than those of White and Asian Americans.<sup>2</sup> This pandemic has magnified the neglect and health disparities in communities of color and has made inequity and institutional racism in our health care system glaringly evident. The data tell an irrefutable story of damaging, avoidable health disparities in communities of color. It is time to consider different health care options and modalities to best meet the diverse needs of our people.

This essay examines the life-changing effect that community health workers (CHWs) have on the health and well-being of marginalized communities by providing culturally informed care that is healing, transformative, and essential for their clients. My own personal experience as a client and as a CHW brings attention to the need for change in social practices and policies that are systemic, subtle, and cumulative and that result in oppression and health inequity.

### Community Health Work

The American Public Health Association defines a community health worker (CHW) as “a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served.”<sup>3</sup> CHWs promote health within a community by assisting individuals to adopt healthy behaviors. They advocate for individual health needs by facilitating effective communication with social aid agencies. They also implement programs that educate clients and promote, maintain, and improve individual and community health. They work in communities, either as part of medical teams in hospitals or providing in-home care as necessary. CHWs typically promote breastfeeding and child nutrition, family planning, immunization, and other behaviors linked to maternal and child health. They also promote awareness about social welfare issues, such as domestic violence or alcohol and drug abuse. CHWs may also provide preventive services such as blood pressure, glaucoma, and hearing screenings.

Most importantly, CHWs are a cost-effective and culturally and community-informed option for providing health care support. They are less expensive than visiting nurses and social workers and provide critical preventative care. Studies show that CHW doula care provides cost savings among Medicaid recipients by **reducing cesarean births**<sup>4</sup>—which cost 50% more than vaginal births<sup>5</sup>—and by reducing the use of epidural analgesia<sup>6</sup> and its associated costs. Doula care thus leads to reduced costs in instrument-assisted births and repeat cesarean births, as well as to improvements in initiation of breast feeding, safe sleep practices, and early implementation of car seats.<sup>6</sup> Moreover, if 90% of mothers in the United States followed breastfeeding recommendations, \$13.8 billion annually could be saved in pediatric health costs and preventing premature deaths.<sup>7</sup> We know that healthier families lead to healthier communities.

For all these reasons, CHWs are key to development and implementation of positive community partnerships and actions that undo the effects of years of racism, discrimination, neglect, and avoidable health inequities (see Figure). CHWs understand the needs of communities of color, which is paramount to successful and cost-efficient interventions.

**Figure.** Descriptions of Community Health Workers in Latinx Communities



© Wandy D. Hernandez-Gordon. Courtesy of HealthConnect One.

It is important for CHWs to understand that the more than 60 million Latinos in the United States<sup>8</sup> represent a diverse community whose members have unique backgrounds, cultures, beliefs, and challenges—especially challenges in accessing health care. Sadly, Latinos are nearly 3 times more likely to be uninsured than non-Hispanic Whites.<sup>9</sup> At this time of great need, job loss, and economic recession, many are unemployed and without employer-provided health insurance. Today, nearly a third of Latinos ages 5 and older are not fluent in English,<sup>10</sup> creating yet another barrier to adequate health care. Health professionals with cultural and language proficiency are critical to successful interventions, including health education, preventative medicine, and treatment. But these interventions are only the start in addressing the higher burdens and challenges that Latinos face in accessing quality health care. It is also critical to dissect and understand the systems and structures that both lead to and exacerbate health inequities.

### Lived Experience of Obstacles

I know firsthand the challenges that Latinos face in obtaining health care. Now a practicing CHW, I had very humble beginnings. My teenage parents were unable to care for me, so my grandparents, who were servant leaders in Puerto Rico, raised me with love. They believed that true leaders served the needs of their communities. I hold this belief close to my heart to this day. My grandmother was a community midwife and mortician. She assisted “*mi gente*,” my people, at the beginning and end of life. The socioeconomic deprivation that I witness within my family and community make me passionate about community health.

My mother struggled with mental illness, and my childhood did not include playing with my friends, jumping rope, or playing hopscotch, but it was rich in knowledge and love. As

an 8-year-old girl, shadowing my grandparents who were CHWs and helping them ensure that community members had proper health care and social services and that their concerns were heard by hospital and clinic professionals, I lived the **community health model**. While other children played with their friends, I knew I had to make sure that I helped a community member get her medication from the local pharmacy. I learned many lifelong lessons as I accompanied elders to the public aid office to help translate and fill out their forms.

To this day, I struggle with the memory of experiencing racism for the first time. A social aid worker quickly transformed into a monster when she realized my grandparents didn't speak English. Her response was hurtful. Clearly annoyed, she snapped, "You should know the language, we are supporting your island." I was a child and felt shocked, numb, and unable to process this cruelty. No child—or any human being, for that matter—should have to experience such ugliness head-on. It is still hard for me to understand the lack of humanity flung at my grandparents at the public aid office. But the real dilemma for society is that these types of interactions prevent people from receiving the health care they need.

This experience led me to educate myself about the application process and build the relationships needed to advocate for, and to help our community gain access to, public aid and health care. Clearly, when seeking medical attention, we all need trust, understanding, accurate information, reassurance, and kindness, along with cultural and language sensitivity. These are basic necessities that help increase access to care and motivate equity. CHWs are the key to restoring equity in low-income communities and communities of color. In particular, doulas are the key to providing much-needed pre- and postnatal support, as health care continues to suffer during this pandemic and period of economic downturn and joblessness.

### **Experience as a CHW**

Like many other CHWs, my life has had many ups and downs that led to my life's work. Those hard lessons that inspire and inform our work make us passionate about being effective CHWs for the community. When I was forced to live with my birth mother, she subjected me to physical and emotional abuse, which made me stronger. Much like the clients I serve today, I became a teen mom and experienced challenges. My upbringing helped me focus on how I could help others in similar situations. My experiences serve as a reminder to always temper my health care knowledge with empathy and patience so that I can adapt to the needs of the communities I work with.

My grandparents, aunts, and friends taught me how to be a mother. My relationships in the maternal health field, including with midwives, nurses, and health care workers, became an invaluable support system. The Latino community protected me, educated me, and spurred my passion for health care in marginalized communities. Because of the community help I received, my 2 grown children enjoyed their youth, broke the teen pregnancy cycle, and have many beautiful memories to share with their own children.

CHWs led me to enroll in a lactation program at a bilingual, bicultural organization. This 10-week breastfeeding training, which included work as a breastfeeding peer counselor and using my daughter as a model, changed my life. Later, I worked at the same center, educating and supporting pregnant women and new mothers about breastfeeding. Again, I used my daughter as a live model. This work led me to get my high school diploma, continue my studies, and ultimately to pursue a CHW career. Now a CHW, I use



the unique skills that I developed as a child and adolescent in my community, coupled with my schooling, to assist my clients and their families. I became a community-based doula, thanks to the HealthConnect One 20-week training course.

Community health changed my life, both as a recipient and as a giver of culturally sensitive care that is based on respect and love. My trajectory exemplifies how CHWs can develop critical skills by living in the communities they are vested in serving. It also shows how invaluable CHWs are in combating implicit bias, racism, and stereotyping that interfere with the quality of care for communities of color. We are in the community and have ourselves experienced implicit bias, racism, and stereotyping in our work and lives. Our critical insight into shared challenges and shared trauma that we bring to the work we do is invaluable in building trust and helping to solve the health care challenges facing the communities we work in.

For most CHWs, addressing the challenges in our community is personal, and CHWs are uniquely qualified and effective in this work. Our personal and professional experiences enable us to understand the unmet basic needs in Latino communities. We are also vested in the local, regional, and national constituents interested in developing equitable grassroots programs to support the CHW profession.

### **A New Kind of Health Care Organization**

HealthConnect One is one example of an organization with a history of working in, for, and with communities to address inequities that Black and Brown people continue to face. The Illinois Community Health Workers Association (ILCHWA), formerly known as the Chicago CHW Local Network, was created by health educator professionals to support, facilitate, and advocate to enhance the CHW workforce. I was the co-founder and vice president of ILCHWA because I am committed to combating the inequities that CHWs face in the health care workforce, and I continue to maintain a vital role in the organization today.

Health organizations that espouse equity and health justice—not just in their vision statement, but also in their day-to-day operations—are much needed. Growing the CHW profession will increase individuals' access to reliable health information, provide them with linguistic and culturally sensitive care, and improve health outcomes for all, regardless of socioeconomic status, background, or identity.

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**Citation**

*AMA J Ethics.* 2022;24(4):E333-339.

**DOI**

10.1001/amajethics.2022.333.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## AMA Journal of Ethics®

April 2022, Volume 24, Number 4: E340-341

### LETTER TO THE EDITOR

#### You Can't Carry a Gun and a Stethoscope at the Same Time

D. Brendan Johnson, MTS

I read the February 2022 issue of the *AMA Journal of Ethics* (“**Tactical Health and Law Enforcement**”) in dismay: How could an entire issue on tactical medicine fail to question a physician’s complicity in violence it assumes? I write from Minneapolis, Minnesota, the city of George Floyd’s murder and a city that in February 2022 witnessed a special weapons and tactics (SWAT) execution of another young Black man, Amir Locke. Black and Brown Americans often experience the police not as a helping presence but as a direct threat: modern American policing has roots in the sporadic slave patrols and militias of the 1700s, which maintained their racialized, violent, and very profitable society.<sup>1</sup>

Medicine is a healing profession and must always attend to the most threatened segments of society. Furthermore, it is a self-regulating profession based on trust, just like the judiciary. And, just like the judiciary, the appearance of impropriety is almost as threatening as the real thing. Consider the “armed tactical physician” who, after apparently stumbling into the role, “needed to improve [his] own firearm skills and tactical knowledge” and who “trained regularly with the SWAT team,” which he identifies as “my team,” eventually earning the affectionate nickname “Doc.”<sup>2</sup> With evident pride, he “had streamlined [his] medical pack to fit the cramped and now comfortably familiar space of [the team’s] armored truck.”<sup>2</sup> I cannot mince words: I do not trust a physician who swears to “do no harm” one day and trains to kill the next.

Police members, like any patients, wholly deserve dignified medical care. If moves towards less lethal weapons or mental health community response teams are in the works, let us offer our expertise. But we must be unflinchingly clear about how we affiliate and identify, lest we streamline our medical ethics to fit the cramped and now uncomfortably familiar space of our violent society.

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**Citation**

*AMA J Ethics.* 2022;24(4):E340-341.

**DOI**

10.1001/amajethics.2022.340.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

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ISSN 2376-6980