From a Long-Term Survivor to Clinicians: A Blueprint for Culturally Competent HIV Care in Latino Communities

Nelson Vergel

Author, HIV Research Advocate

Founder, Program for Wellness Restoration

The Weight of History: A 40-Year Survival Story.



Dec 1984

Arrival in the U.S.



June 1986

HIV Diagnosis

Chemical engineer by day, counselor by night.

1986–1993

The Era of Secrecy

Diagnosis hidden from employers and family. Revealed only upon partner's death.



1986–1996



The Era of Loss

Over 35 friends died in a single decade.

1994

Shift to Advocacy

Created non-profit, lectured nationwide. Wrote "Built to Survive"



1997



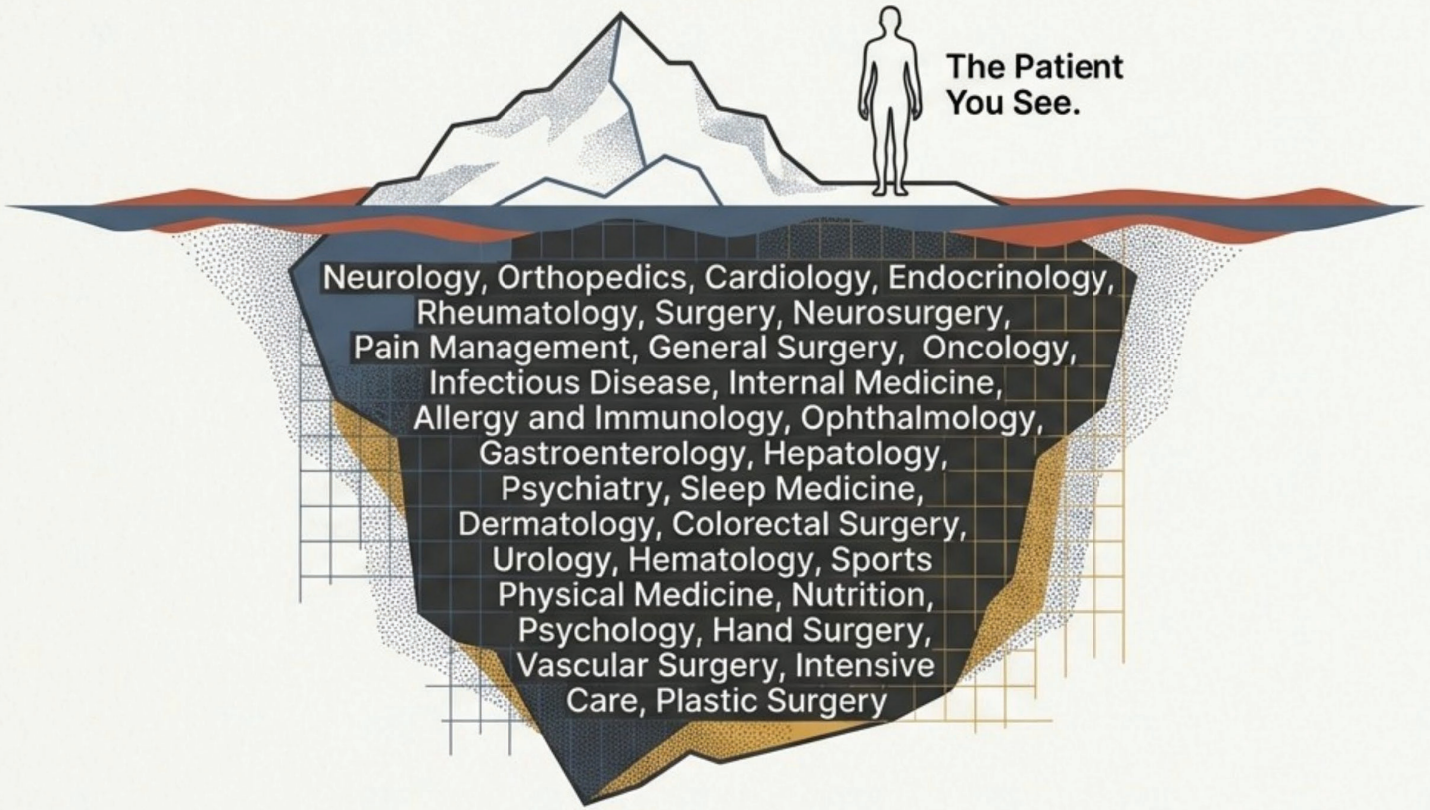
The Turning Point

New HIV medications change survival outlook.

Clinical Application

Understanding the historical context of HIV, particularly the era of profound loss and secrecy, is crucial for culturally competent care. Acknowledge and honor the long-term survivor's journey, recognizing the psychological impact of witnessing mass death and the evolution of treatment. Foster a therapeutic environment that validates their resilience and addresses the unique challenges of aging with HIV.

The “Iceberg” of Survival: Managing Medical Complexity



158

CPT Codes

In patient records since 2009

32

Specialists

Distinct medical disciplines visited

Clinical Application

Recognizing the full extent of a patient’s complex medical journey, including the multitude of specialists and procedures, is vital for comprehensive and empathetic care. Acknowledge the burden of this history and coordinate care to reduce fragmentation and improve outcomes.

Narrative Takeaway: When a patient enters your office, they carry the history of hundreds of prior interactions.

Bridging the Gap: Culturally Responsive Care for Latino Patients

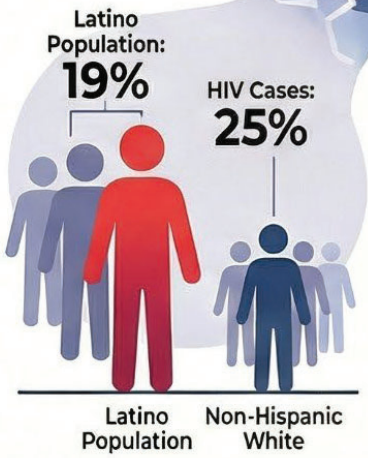
BARRIERS TO EFFECTIVE CARE



HIGH RISKS IN COMMUNICATION

Limited English proficiency patients have double the risk of serious medical errors.

	Latino Population	Non-Hispanic White
Uninsured Rate (2023)	20%	6%
Proficient Health Literacy	Lower than average	12% of U.S. Adults





THE BURDEN OF COMPLEX CARE

Long-term survivors may see over 30 different medical specialists for various diagnoses.

CULTURALLY RESPONSIVE SOLUTIONS



PRACTICE FAMILISMO AND PERSONALISMO

Prioritize warm greetings and involve family members in medical decision-making processes.



REMOVE COMMUNICATION FRICTION

Use professional interpreters instead of family members and provide bilingual visual materials.



BUILD RAPPORT THROUGH PRESENCE

Read charts before entering and avoid typing while the patient is speaking.

The Changing Landscape: Why Cultural Competence is a Business Necessity



65 Million

Latinos in the U.S. (19.5% of total population)



71%

Of all U.S. population growth is attributed to Latinos



1 in 4

Children under 18 in the U.S. are Latino



437,000+

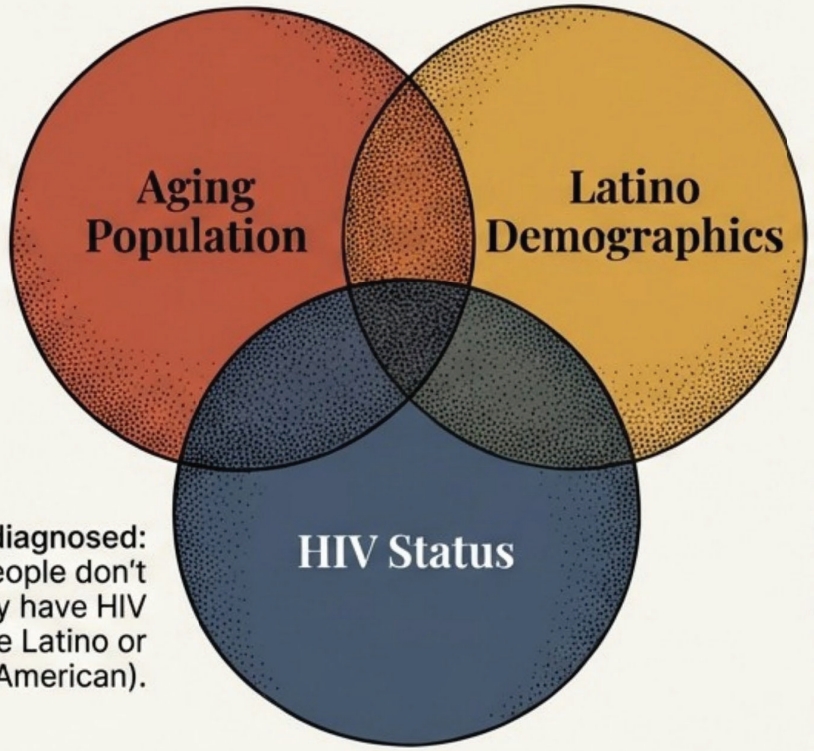
Latino immigrants in 2023 accounted for 1/3 of the group's growth

Clinical Application

Recognizing these demographic shifts is essential for sustainable healthcare business models. Implement culturally competent care strategies, including language access, diverse workforce representation, and community engagement, to build trust and meet the unique needs of growing Latino populations, thereby improving patient outcomes and reducing disparities.

The Intersection of Demographics and Epidemiology: HIV in 2024

The Aging Cohort: >50% of the 1.3 million people with HIV are over 50 years old.



Disproportionate Burden: Latinos are 18% of US population but 25% of people with HIV.

The Undiagnosed: ~200,000 people don't know they have HIV (60% are Latino or African American).

Clinical Reality

- Polypharmacy Risks
- Top Issue: Chronic Pain
- Key Concept: U=U (Undetectable = Untransmittable)

Clinical Application

Acknowledge the aging cohort and disproportionate burden of HIV among Latinos. Integrate cultural competence and age-inclusive care strategies, address polypharmacy and chronic pain, and actively promote the U=U message to improve testing, engagement, and health outcomes.

The Language Gap: A Critical Safety Issue

- 35% of foreign-born Latinos in the U.S. speak only Spanish.

2x Higher Risk

of serious medical events due to communication errors for Limited English Proficiency (LEP) patients. (Source: Flores, G., NEJM)

Clinical Application: Interpretation Standards

DON'T: Rely on family members, especially children, to translate. This leads to misdiagnosis, emotional burden on the child, and poor adherence.

DO: Emphasize and utilize trained medical interpreters.



Decoding *Familismo*: Family as a Clinical Asset



Cultural Insight: *Familismo* is a core value emphasizing close family ties and collective decision-making. In this context, the individual's health is often viewed as a family matter.

Recommendation

Align with cultural expectations to build trust.

"Always ask if the patient wants a family member involved in medical decisions."

Involving the family unit often improves treatment adherence and creates a stronger support network for the patient.

The Power of *Personalismo*: Warmth Before Business



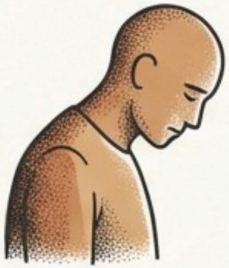
Cultural Insight: *Personalismo* refers to the high value placed on warm, friendly, personal relationships over purely transactional ones.

The Friction Point: A 'strictly business' approach can be perceived as cold or dismissive.

Clinical Application: The Rapport Protocol

- ✓ Greet patients warmly using their names.
- ✓ Engage in brief small talk *before* diving into clinical questions.
- ✓ Outcome: This slight investment in time builds the rapport necessary for honest disclosure of symptoms.

Addressing Internal Barriers: Fatalism and Fear



Fatalism

The Barrier: Some patients may view illness as fate or punishment, leading to a passive approach to preventive care.

Strategy: Respectfully acknowledge beliefs but counter with stories/ examples promoting early detection and chronic disease management.



Immigration Fear

The Barrier: Fear of deportation or discrimination can silence open dialogue.

Strategy:

1. Explicitly assure confidentiality.
2. Refrain from asking about immigration status.
3. Display multilingual signs welcoming all patients.

Recommendation

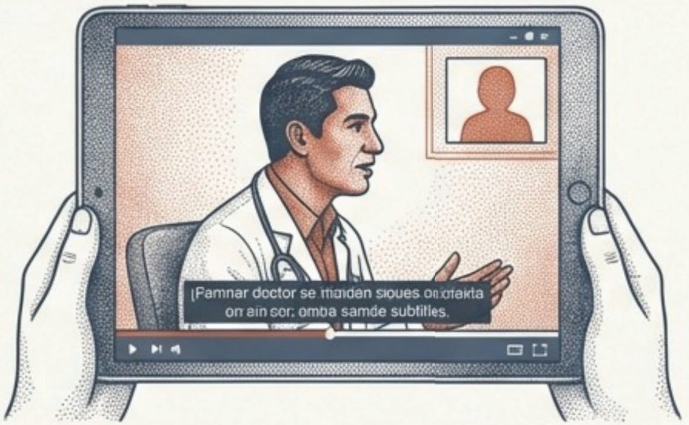
Adopt a patient-centered approach by actively listening to fears without judgment, validating feelings, and emphasizing empowerment through education and confidentiality assurance to build trust and improve engagement in care.

Bridging the Trust Gap in Research and Prevention

The Challenge: During the COVID-19 pandemic, Latino adults were 1.5x more likely than Whites to express concern about vaccine safety (Source: KFF).

Clinical Application: The Messenger Matters

- **The Framework:** Frame discussions in culturally appropriate ways, citing community health benefits (protecting the family).
- **The Messenger:** Use trusted voices, such as Latino healthcare professionals or *promotoras* (community health workers).



Visual Representation: Encourage hospitals to offer Spanish-language video content and ensure brochures feature images reflecting Latino patients.

Inside the Exam Room: Etiquette for Connection

Tips for Your Future Practice



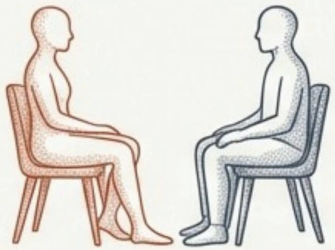
1. The Entry:

Read the chart *before* you knock. Asking a patient to repeat their entire history signals disrespect.



2. The Intro:

Introduce yourself by name and role to reduce anxiety.



3. The Posture:

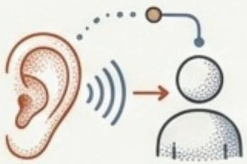
Sit down. This signals that the conversation is relaxed and you are not rushing to the door.

> **"Try to look at us more than the chart."**



4. The Screen:

Do not type while talking unless you are actively showing the patient the screen.



5. The Listening:

Let the patient finish sentences. They often build to the most important point at the end.

Clinical Application

Consistently practice these etiquette points to foster a therapeutic alliance, build trust, and ensure patients feel heard and valued, ultimately improving communication and clinical outcomes.

Operational Sensitivity: Beyond the Doctor

The Front Line: Your support and front desk staff make or break your practice.

Time Management

- Apologize for long waits.
- Do not appear rushed; prioritize “Patient Care” over “Business Metrics” in the room.

Handling the “Informed” Patient

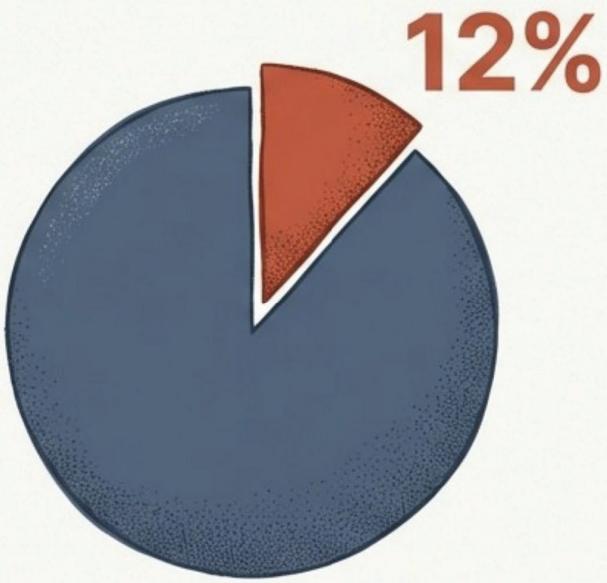
- Avoid labeling patients who ask many questions or cite the Internet as “difficult”.
- Never dismiss advice from other providers in front of the patient—it erodes trust in the entire medical system.



Clinical Application

Train front-line staff to practice active listening and convey warmth. Implement protocols for managing delays and handling patient questions respectfully to maintain trust and a positive patient experience.

Navigating Health Literacy and Communication



Only 12% of U.S. adults have proficient health literacy. Rates are lower in Spanish-speaking populations (Source: National Assessment of Adult Literacy).

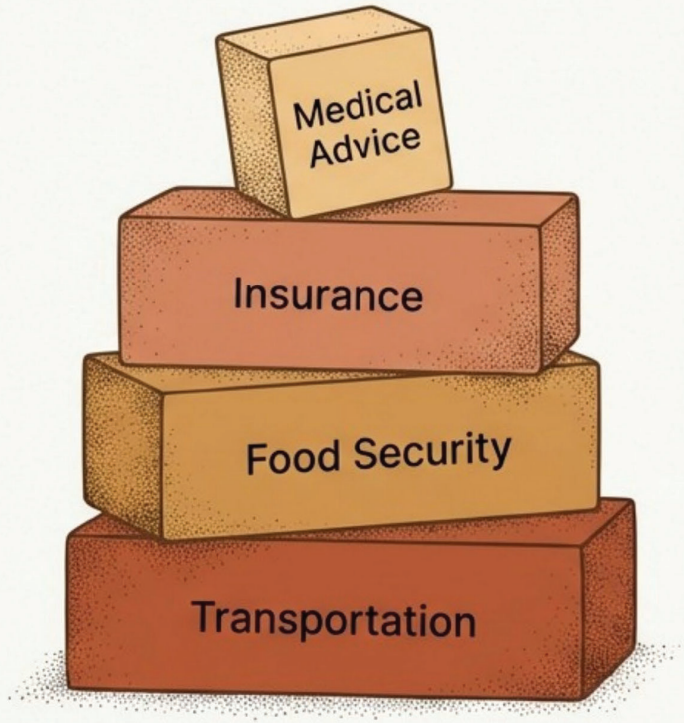
Clinical Application: Bridge the Gap

- **Materials:** Provide easy-to-read materials in both English and Spanish. Use visuals, avoid jargon.

- **Pre-Visit Prep:** Have support staff encourage patients to write down symptoms and questions **before** the visit to overcome cultural hesitation or language recall issues.



Social Determinants of Health (SDOH)



Medical advice cannot exist in a vacuum.

Key Statistics & Barriers

- **20%** of Latinos in the U.S. are uninsured (vs. 6% of non-Hispanic Whites).
- Common barriers: Food insecurity, Lack of transportation.

Recommendation

- Screen for these specific barriers during intake.
- Offer social service referrals when possible.
- Advocate for patient-care navigators.

Summary: Empathy into Action

Key Takeaways for Your Practice

1. **Respect History:** Acknowledge the trauma and complexity of long-term survival.
2. **Invite Support:** Encourage patients to bring a friend or family member if they have low self-advocacy skills.
3. **Check Sensitivity:** Validate that the environment (from signs to staff) is welcoming and culturally attuned.



"If you don't know the answer, please say so."
– "Honesty builds the ultimate trust."

Clinical Strategies and Considerations for Latino Patients with HIV

Based on 1 source

Focus Area	Key Insight or Barrier	Recommended Clinical Action	Relevant Statistic (Inferred)
HIV Care & Clinical Engagement	Latinos are disproportionately affected by HIV and often diagnosed later in the disease progression.	Communicate U=U (Undetectable = Untransmittable), address polypharmacy in aging patients, and utilize patient-care navigators to improve retention in care.	Hispanic/Latino people account for 18% of the U.S. population but 25% of people living with HIV; 60% of undiagnosed cases occur among Latino and Black populals
Cultural Values	Familismo: A strong cultural value emphasizing close family ties and collective decision-making.	Inquire if the patient prefers to have family members involved in medical decisions to align with cultural expectations and improve support.	Approximately 1 in 4 children under 18 in the U.S. are Latino, highlighting the central role of youth in family structures.
Language Access	Significant portions of the population have Limited English Proficiency (LEP); 35% of foreign-	Use professional medical interpreters rather than family members; provide bilingual materials and avoid medical jargon.	LEP patients have a 2x higher risk of socis medical events due to communication errors.
Systemic Barriers	Social Determinants of Health: Latinos face high rates of being uninsured, food insecurity, and	Screen for social determinants of health and provide social service referrals; refrain from asking about immigration status to maintain safety.	As of 2023, 20% of Latinos in the U.S. are uninsured compared to 6% of non-Hispanic Whites.
Trust and Rapport	Fear regarding immigration status or experiences with discrimination can prevent open dialogue and	Assure patients of confidentiality, display multilingual welcoming signs, and include Latino healthcare workers in community outreach.	Approximately 437,000 Latino immigrants arrived in the U.S. in 2023, many of whom may have high sensitivity regarding legal
Trust and Rapport	Fear regarding immigration status or experiences with discrimination can prevent open dialog	Assure patients of confidentiality, display multilingual welcoming signs, and include Latino healthcare workers in community outreach.	Latino adults were 1.5× more likely than Whites to express concern about vaccine safety during the pandemic.
Provider Behavior	Medical distrust and fatalism (belief that illness is predestined) can reduce engagement in	Acknowledge beliefs respectfully, sit during visits, avoid typing while talking, and review charts before entering the room to demonstrate presence.	Latino adults were 1.5× more likely than Whites to express concern about vaccine safety during the pandemic.

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1. Flores G. The impact of medical interpreter services on the quality of health care: a systematic review. ***Medical Care Research and Review***. 2005;62(3):255–299. [Language Gap / 2× higher risk of serious medical errors for LEP patients]

2. National Assessment of Adult Literacy (NAAL). U.S. Department of Education, National Center for Education Statistics. ***nces.ed.gov/naal***. [Only 12% of U.S. adults have proficient health literacy; rates lower in Spanish-speaking populations]

3. U.S. Census Bureau. Hispanic or Latino Origin Population Statistics, 2023. ***census.gov***. [65 million Latinos in U.S., 19.5% of population; 71% of U.S. population growth; 1 in 4 children under 18 are Latino]

4. Centers for Disease Control and Prevention (CDC). HIV Surveillance Report, 2022. ***cdc.gov/hiv***. [Latinos are 18–19% of U.S. population but account for 25% of people living with HIV; >50% of 1.3 million people with HIV are over 50]

5. HIV.gov / CDC. Undiagnosed HIV Infections. ***hiv.gov***. [~200,000 people unaware of their HIV status; 60% are Latino or African American]

6. U.S. Department of Health and Human Services, Office of Minority Health. Uninsured Rates Among Hispanic/Latino Populations. ***minorityhealth.hhs.gov***. [20% of Latinos uninsured in 2023 vs. 6% of non-Hispanic Whites]

7. KFF (Kaiser Family Foundation). COVID-19 Vaccine Monitor: Latino Adults and Vaccine Hesitancy, 2021. ***kff.org***. [Latino adults were 1.5× more likely than Whites to express concern about vaccine safety during the pandemic]

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9. Sobralske M. Health care seeking among Mexican American men. ***Journal of Transcultural Nursing***. 2006;17(2):129–138. [Personalismo: high value placed on warm, personal relationships in healthcare]

10. Juckett G. Caring for Latino patients. ***American Family Physician***. 2013;87(1):48–54. [Fatalism, fatalismo, and its impact on preventive care engagement among Latino patients]

11. Department of Homeland Security. 2023 Yearbook of Immigration Statistics. ***dhs.gov***. [437,000+ Latino immigrants in 2023 accounted for approximately 1/3 of group's growth]

12. Undetectable = Untransmittable (U=U). Prevention Access Campaign. ***preventionaccess.org***. [U=U: People with HIV who achieve and maintain an undetectable viral load cannot sexually transmit HIV]

13. Vergel N. ***Built to Survive: A Comprehensive Guide to the Medical Use of Anabolic Therapies, Nutrition and Exercise for HIV(+) Men and Women***. 1999. [Referenced in presenter's 40-year survival narrative and advocacy work; founding of PoWeR in 1994]

14. HIV Long-Term Survivors. Medical Complexity in Aging HIV-Positive Individuals. ***Journal of Acquired Immune Deficiency Syndromes***. [Long-term survivors may see 30+ different medical specialists; polypharmacy risks in aging HIV-positive cohort]

Thank You.

Questions?

Contact me at
NelsonVergel@gmail.com