Palliative and End of Life Care in Immigrants and Refugees

May 12, 2025

Minnesota Center of Excellence in Newcomer Health

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Acknowledgment

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The Minnesota Medical Association facilitated the CMEs.

No financial conflicts of interest.

DENVER HEALTH est. 1860 FOR LIFE'S JOURNEY

HealthPartners Institute

Children's Hospital of Philadelphia

Jefferson Health

DEPARTMENT OF HEALTH

UC San Diego School of Medicine Department of Pediatrics

Refugee HEALTH UNIT UC SAN DIEGO CENTER FOR COMMUNITY HEALTH

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Learning Objectives

- Describe demographic trends, disparities, and healthcare barriers in palliative and end of life care
- Recognize how the principles of cultural humility can be applied to palliative and end of life care of immigrants and refugees
- Identify at least two strategies to address barriers and close disparity gaps in palliative and end of life care for immigrants and refugees

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Agenda

- Background
- Centering Culture and Cultural Humility
- Lifelong Commitment to Learning and Critical Self-Reflection
  - Hierarchy of Communication Needs
  - Family Systems Lens
- Recognizing and Challenging Power Imbalances
- Developing Partnerships
- Q&A

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Today's Speakers

Miguel Ruiz Diaz, MD

HealthPartners

University of Minnesota

Cristina Plaza Ruiz, EdD, LMFT

VIA Counseling and Consulting, LLC

Bethel University

Brett Hendel Paterson, MD, SFHM, FASTMH

HealthPartners

University of Minnesota

(Moderator)

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Reflection

- What matters most to you?
- What would be more meaningful to you if you had a serious illness and were approaching your end of life?

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A lens to approach conversations that shift the focus

- From cultural competence to **cultural humility**
- From patient-centered approaches only to **patient/family-centered** care and decision making
- From the medical model of understanding illness and dying to the **meaning** that these may have for the patient/family

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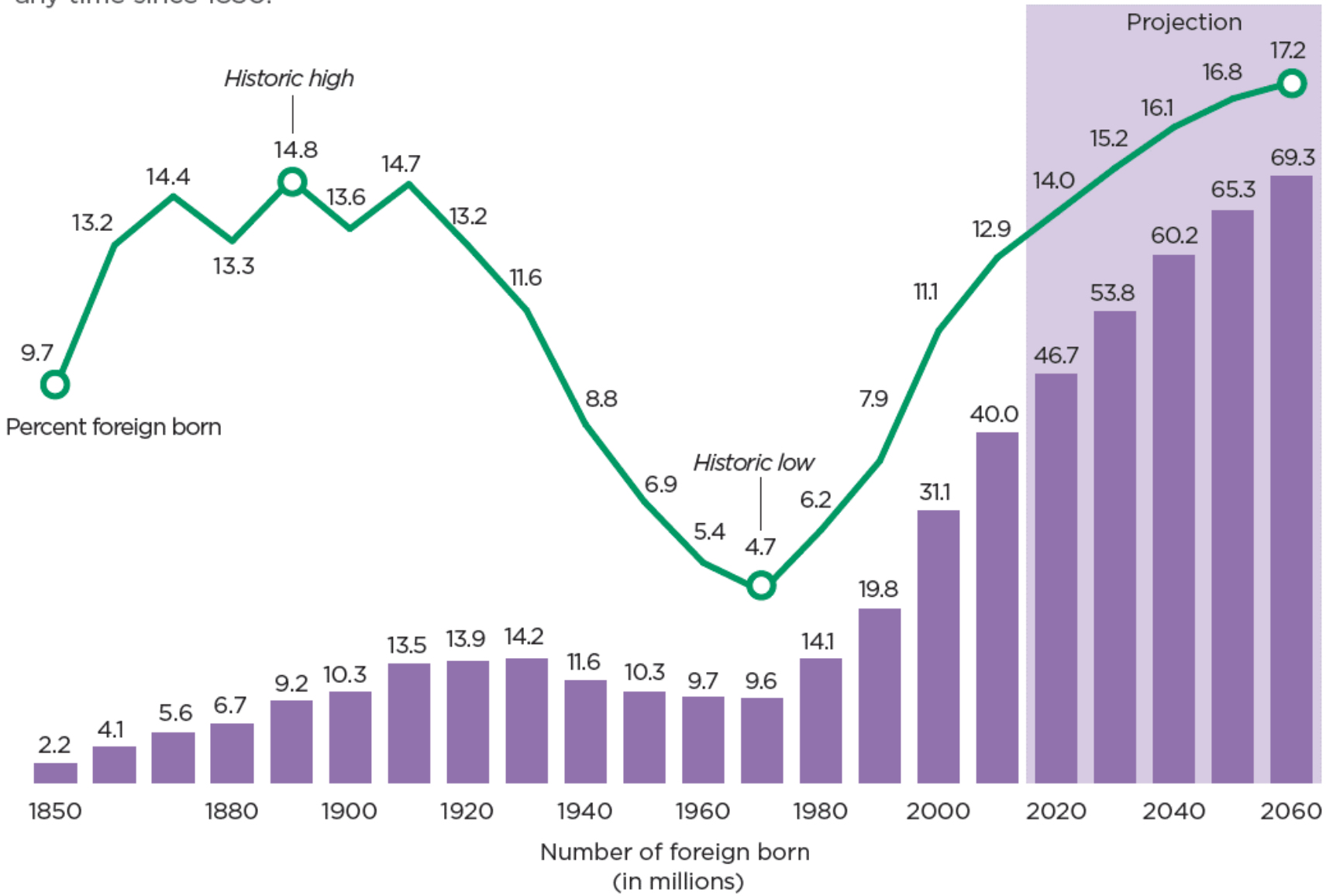
Foreign-Born People Living in the United States: 1850 to 2010, Projected 2020 to 2060

By 2028, the foreign-born share of the U.S. population is projected to be higher than at any time since 1850.



Source: U.S. Census Bureau, 1850–2000 Decennial Censuses, American Community Survey 2010, 2017.
Demographic Turning Points for the United States: Population Projections for 2020 to 2060 (www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1144.pdf)

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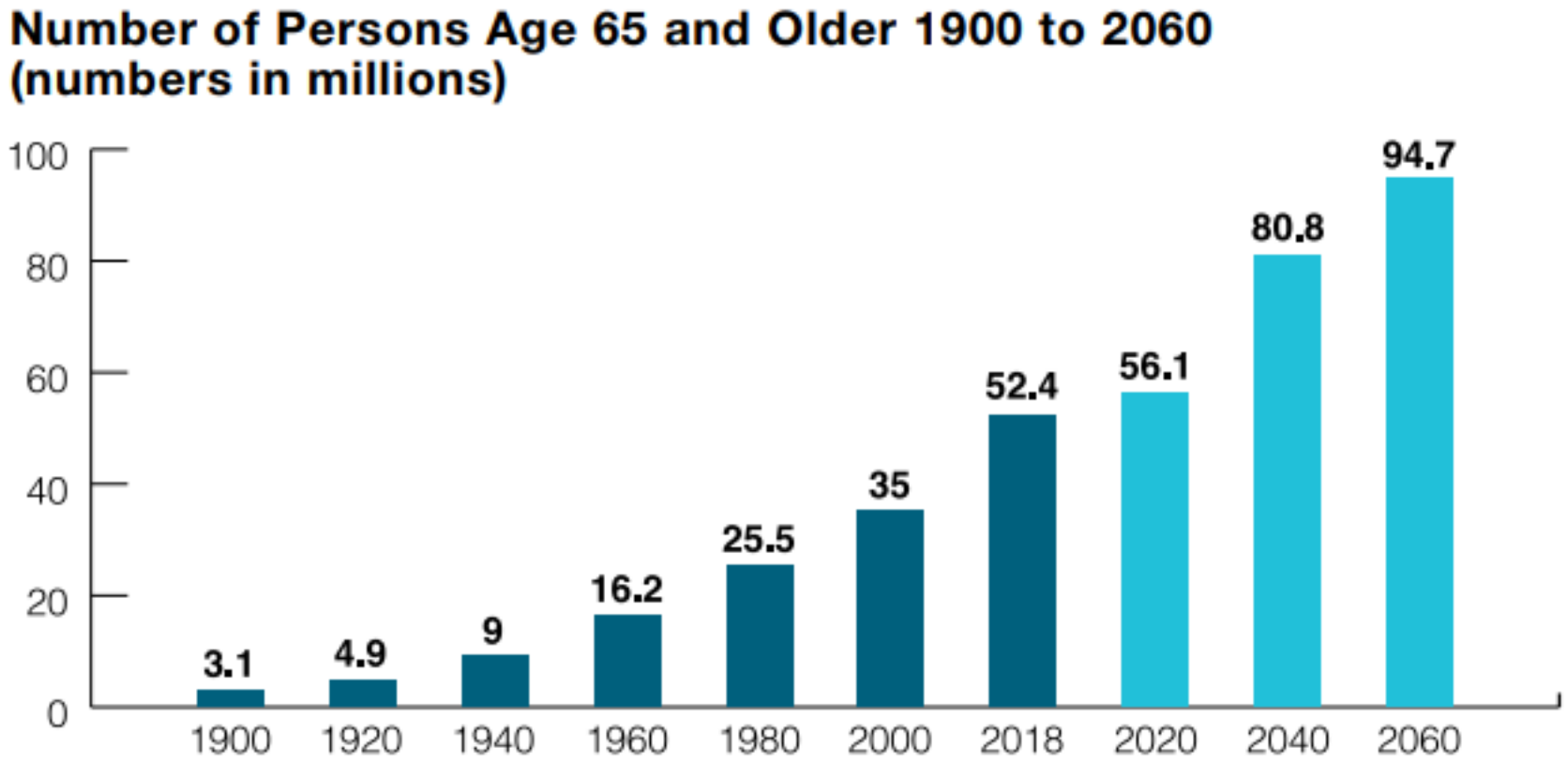

- Over 23% of older adults in the U.S. are racial/ethnic minority
- 9% Black → 88%
- 8% Latino → 175%
- 5% Asian / Pac Islander → 113%
- 0.5% Native American → 75%

Between 2018 and 2040, the white (not Hispanic) population age 65 and older is projected to increase by 32% compared to 125% for older racial and ethnic minority populations

Source: 2018 U.S. Census Bureau, Population Estimates and Projections

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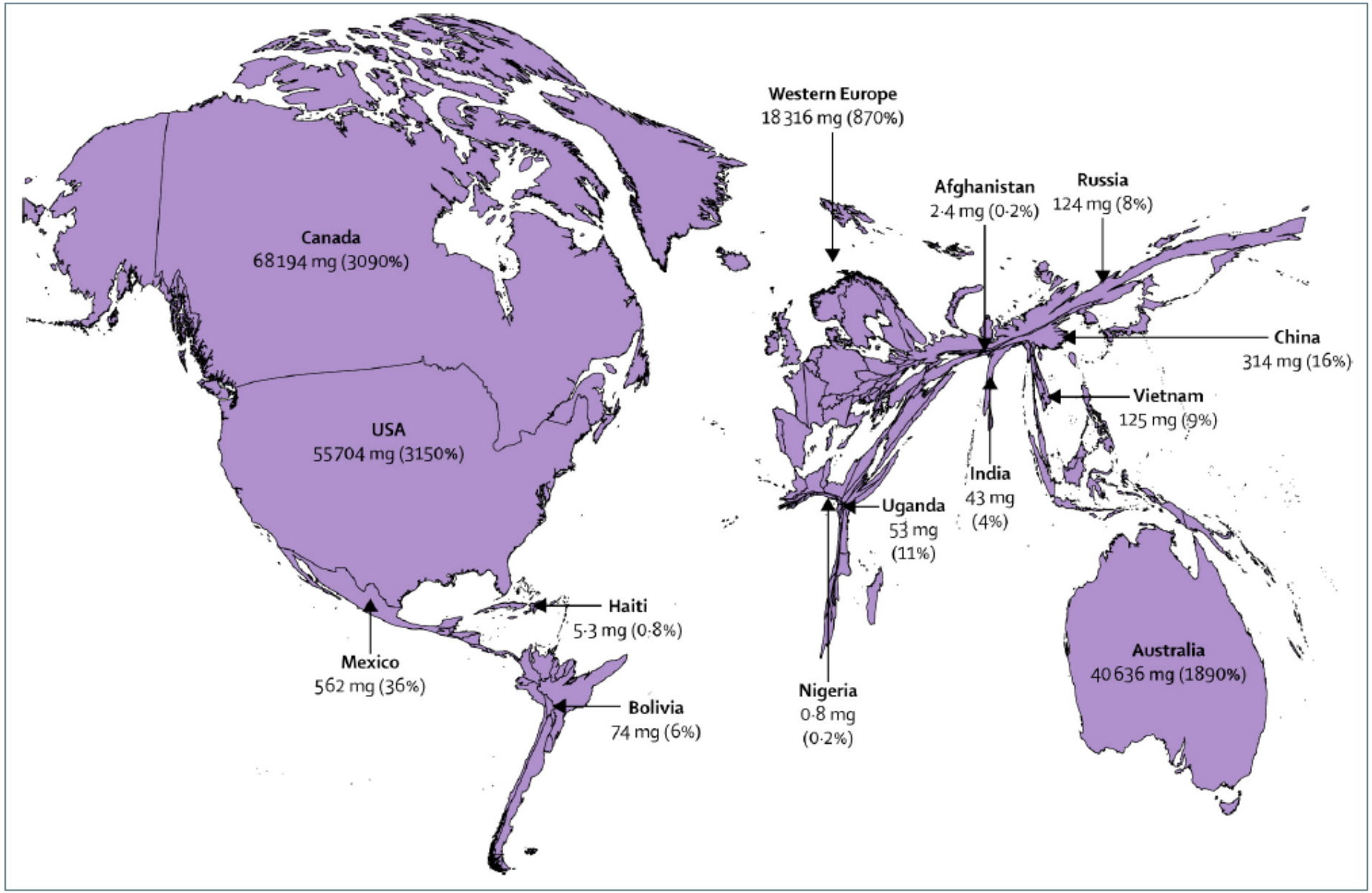


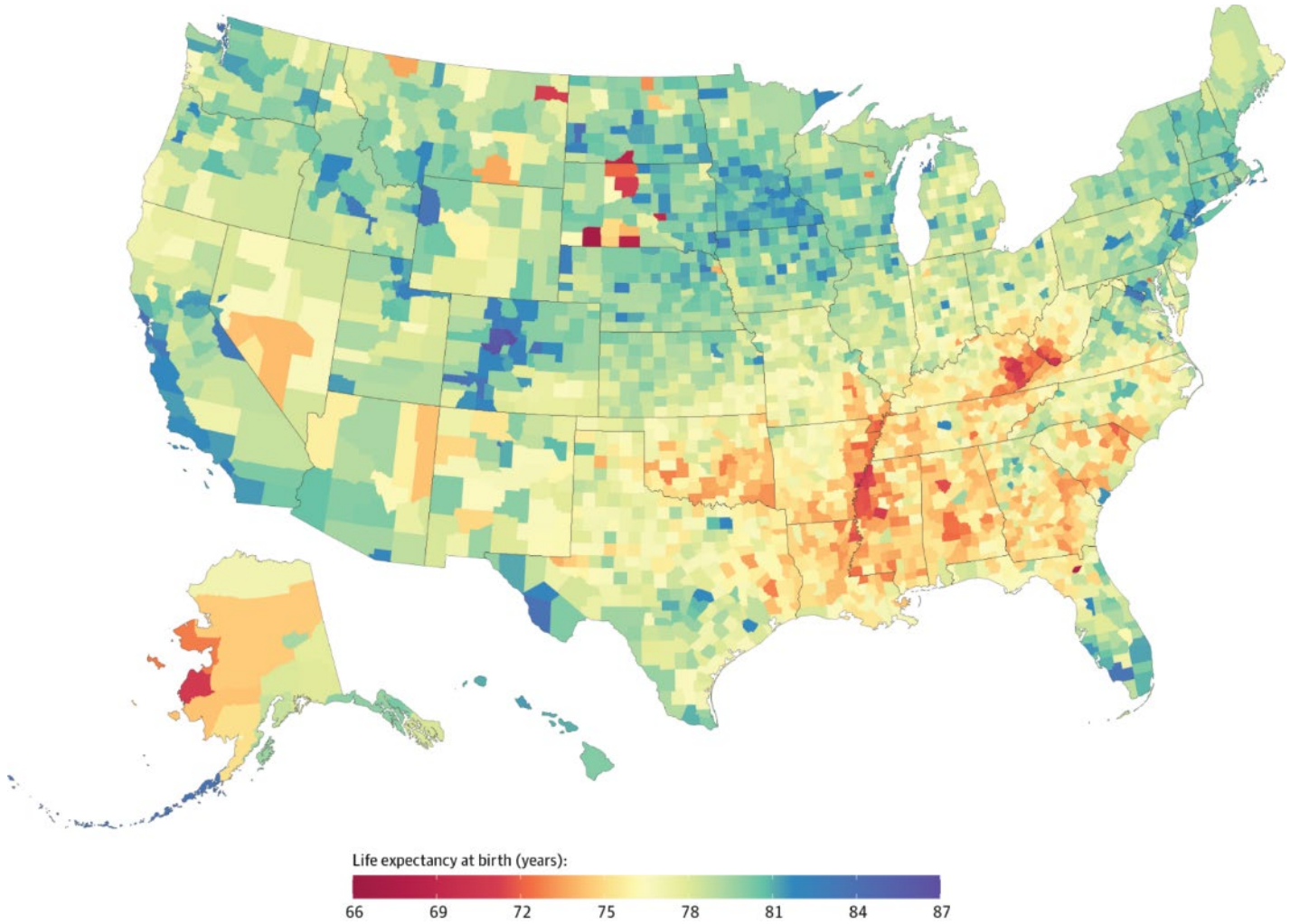
Figure: **Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering**

Source: Knaul FM, Farmer PE, Krakauer EI, et al (2017).[1]

Knaul FM, Farmer PE, Krakauer EI, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *Lancet* 2017

JAMA Internal Medicine | Original Investigation | HEALTH CARE POLICY AND LAW

Inequalities in Life Expectancy Among US Counties, 1980 to 2014



JAMA Intern Med. 2017;177(7):1003-1011. doi:10.1001/jamainternmed.2017.0918

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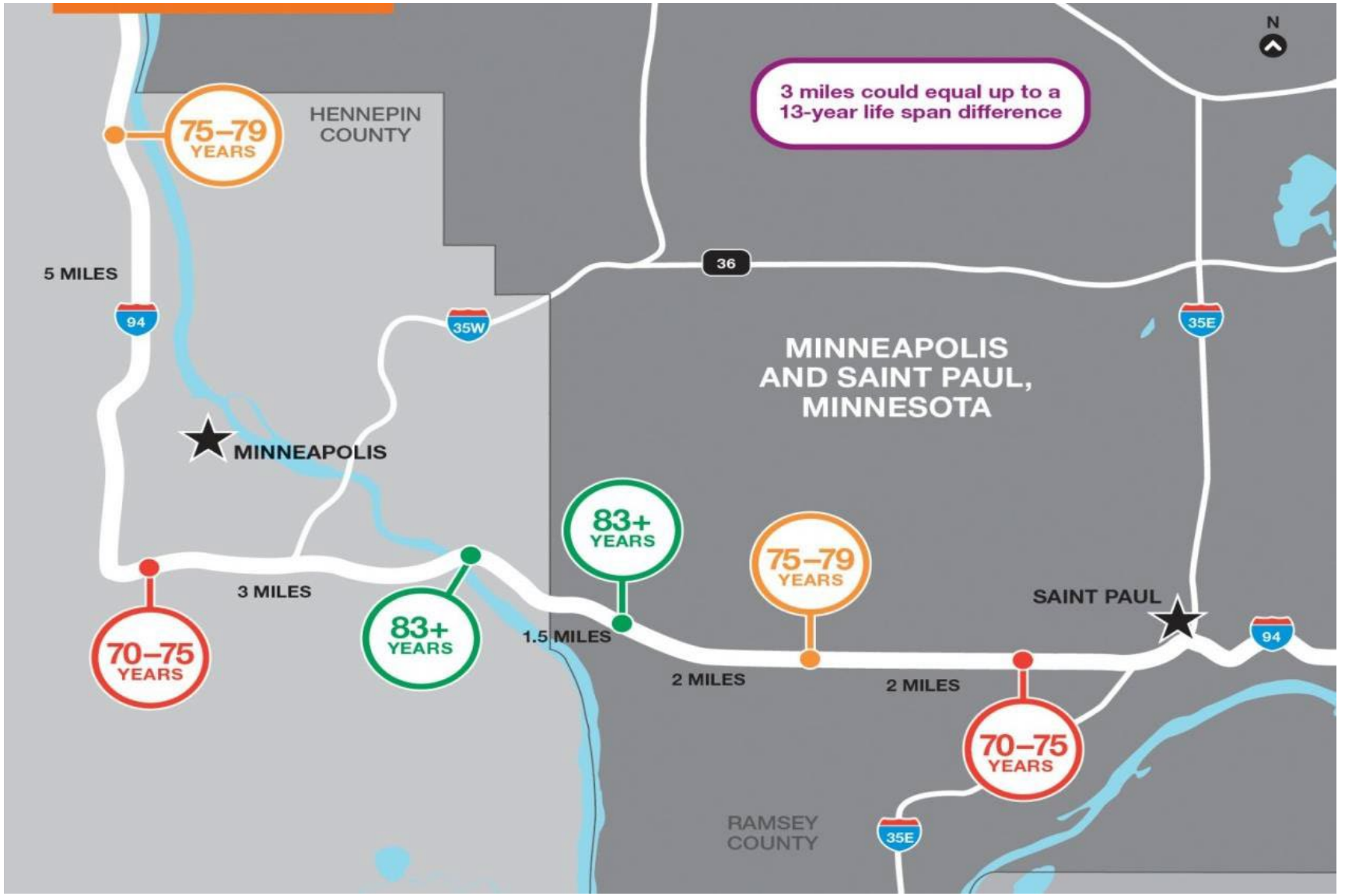
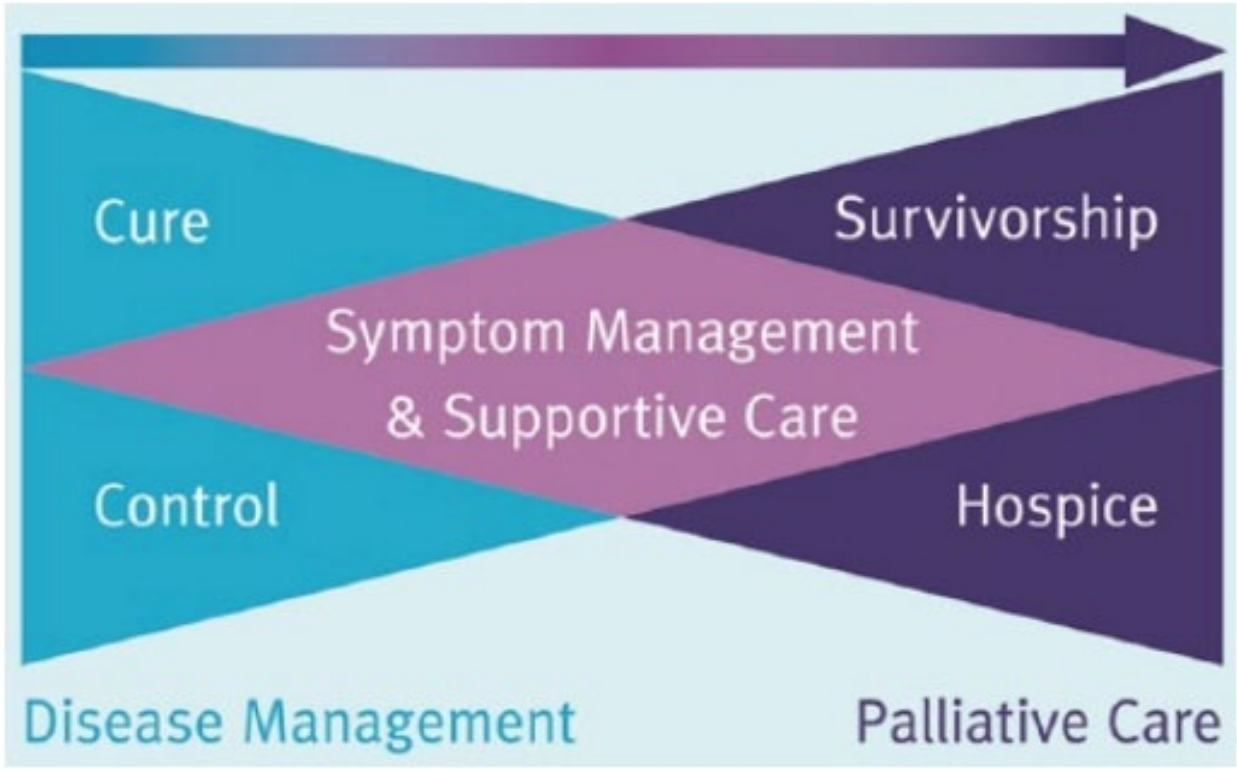
Life Expectancy in Twin Cities – 13 years

Zip code is more important than genetic code

[Map: The Neighborhood You're From & Life Expectancy (https://streets.mn/2013/07/18/map-the-neighborhood-youre-from-life-expectancy/)]



Hospice and Palliative Care



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Hawley P. Barriers to Access to Palliative Care. Palliative Care: Research and Treatment. 2017;10. doi:10.1177/1178224216688887

JAMA | Original Investigation | CARING FOR THE CRITICALLY ILL PATIENT

Association Between Immigrant Status and End-of-Life Care in Ontario, Canada

Christopher J. Yarnell, MD; Longdi Fu, MSc; Doug Manuel, MD, MSc; Peter Tanuseputro, MD, MHSc; Therese Stukel, PhD; Ruxandra Pinto, PhD; Damon C. Scales, MD, PhD; Andreas Laupacis, MD, MSc; Robert A. Fowler, MDCM, MS(Epi)

End-of-Life Care Among Immigrants

Disparities or Differences in Preferences?

Michael O. Harhay, PhD; Scott D. Halpern, MD, PhD

JAMA. 2017;318(15):1479-1488. doi:10.1001/jama.2017.14418
JAMA October 17, 2017 Volume 318, Number 15

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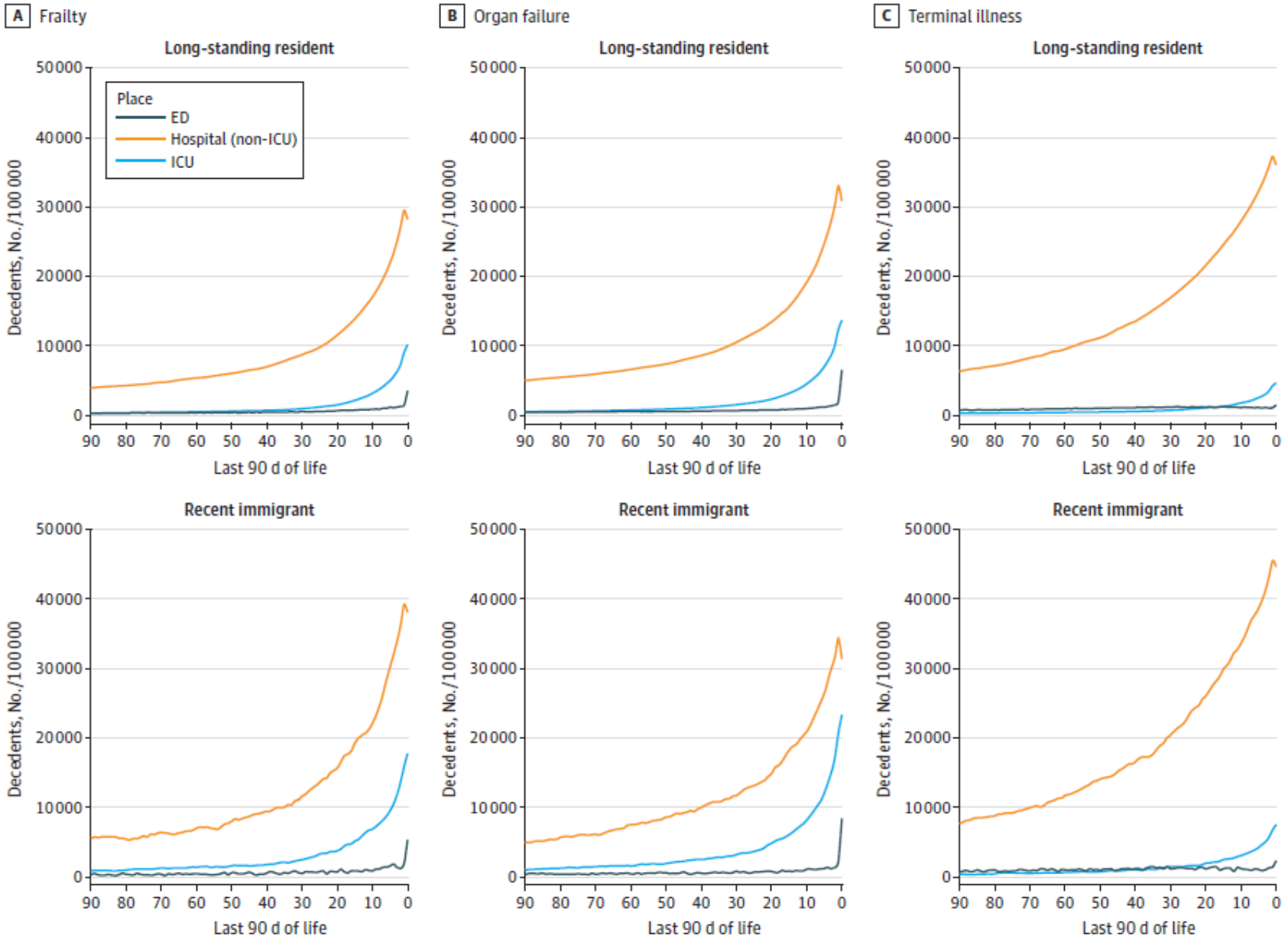
Figure 2. Comparison of the Places of Care in the Last 90 Days Among Recent Immigrants and Long-standing Residents Stratified by the Cause of Death



JAMA Network Open. 2021;4(11):e2132397. doi:10.1001/jamanetworkopen.2021.32397

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HOME:
Understanding End-of-Life Preferences Across Cultures

- Dying at home is often preferred in the U.S. for peace, privacy, and comfort.
- In many cultures, hospitals symbolize safety and trusted care.
- Dying at home may feel like abandonment or neglect to some families.
- Cultural context shapes beliefs around where a “good death” happens.

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Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study

- Finances/health insurance barriers
- Doctor behaviors
- Communication chasm between doctors and patients
- Family beliefs and behaviors
- Health care system barriers
- Cultural and religious/spiritual barriers

Periyakoil Vyjeyanthi et al. J of Palliative Medicine. April 2016, 19(4): 373-379.

Public Health Crisis

The need to ensure culturally appropriate, high-quality End of Life care for diverse Americans is not only a national priority but also perhaps the largest public health crisis looming over our nation.

J Pal. Med. 2016 Apr 1; 19(4): 373–379

Centrality of Culture in Health Care

Culture fundamentally shapes how individuals make meaning out of illness, suffering, and dying, and it strongly influences people's responses to diagnosis, illness, and treatment preferences.

Elk, R et al. Health Equity 2020 Vol. 4, No. 1

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Palliative Care Specialists Series -
Christopher A. Jones and Arif H. Kamal
Feature Editors:

Top Ten Tips Palliative Care Clinicians Should Know About Caring for Muslims

Tip 1: The Five Daily Prayers and Recitation of Qur'an Are Central to How Many Muslims Make Meaning and Cope with Life-Limiting Illness

Tip 2: Muslims May Want to Involve Religious Leaders or An Imam When Faced with Illness

Tip 3: Clinicians Should Recognize That Disclosure of Information, Informed Consent, and Medical Decision-Making May Differ from Western Views in the Muslim Family

Tip 4: Fasting During the Holy Month of Ramadan and Other Dietary Restrictions Should Be Explored by Clinicians as It Can Impact Medical Care

Tip 5: Respecting the Modesty and Privacy Upheld by the Muslim Patient Is Central to Culturally Sensitive Care

Tip 6: Advance Care Planning Is Acceptable But Not Fully Embraced

Tip 7: Muslim Patients May Hesitate to Utilize Analgesic Regimens and Palliative Sedation

Tip 8: Considerations When Exploring Redirection of Care/Physician-Assisted Death/Life Prolongation

Tip 9: Post-Mortem Care for the Muslim Patient

Tip 10: Palliative Care Considerations in the Muslim Child

Madni, A., Khan, S., Bilbeisi, T., Pasli, M., Sakaan, F., Lahaj, S. M., Patel, R., & Kamal, A. H. (2022). Top Ten Tips Palliative Care Clinicians Should Know About Caring for Muslims. *Journal of palliative medicine*, *25*(5), 807–812. https://doi.org/10.1089/jpm.2021.0575

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Cultural Humility

- Lifelong commitment to learning
  - Challenging assumptions
- Identifying Power Dynamics
  - Challenging power imbalances
- Developing Partnerships
  - Challenging individualism

Tervalon, M and Garcia-Murray, J, J Health Care Poor Underserved . 1998 May;9(2):117-25.

52-year-old man from Mexico with dysuria

- Delayed visit: Penile mass
- Delayed bx confirms cancer (scc)
- Delayed partial penectomy
- Delayed staging IIB Grade 2
- Delayed inguinal node dissection
- Chemo/Radiation
- Delayed f/u, recurrence, stage IV

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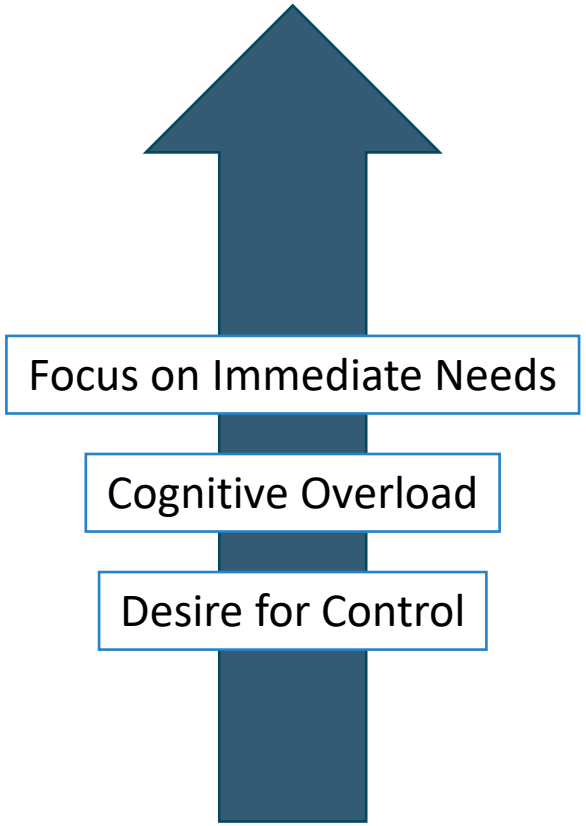
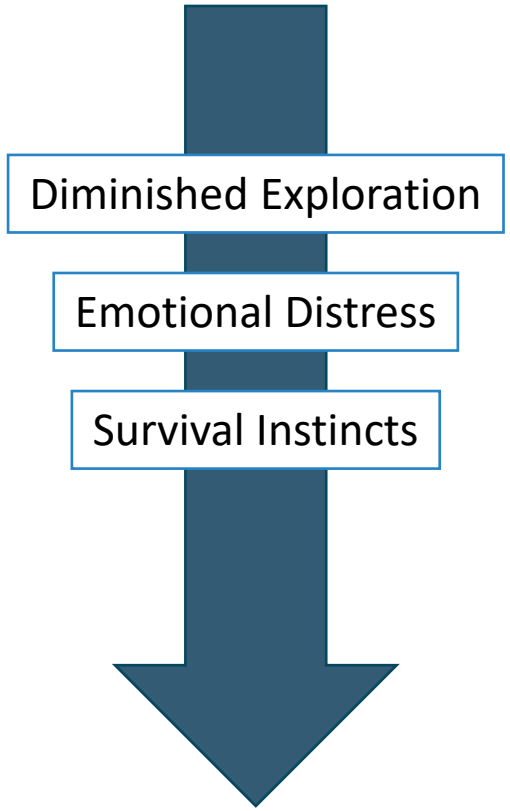
1. Lifelong Commitment to Learning and Critical Self-Reflection

- What may be some of the assumptions or biases that other people (or you) may have?
- What feelings do you experience, and how are those changing as you learn the patient's story better?
- How can we suspend judgment and remain respectfully curious?

CURIOSITY



CERTAINTY



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1. Lifelong Commitment to Learning and Critical Self-Reflection (continued)

- Look in the mirror
- Suspend judgement
- “I don’t know”
- Be okay with discomfort
- Be curious
- Develop trust

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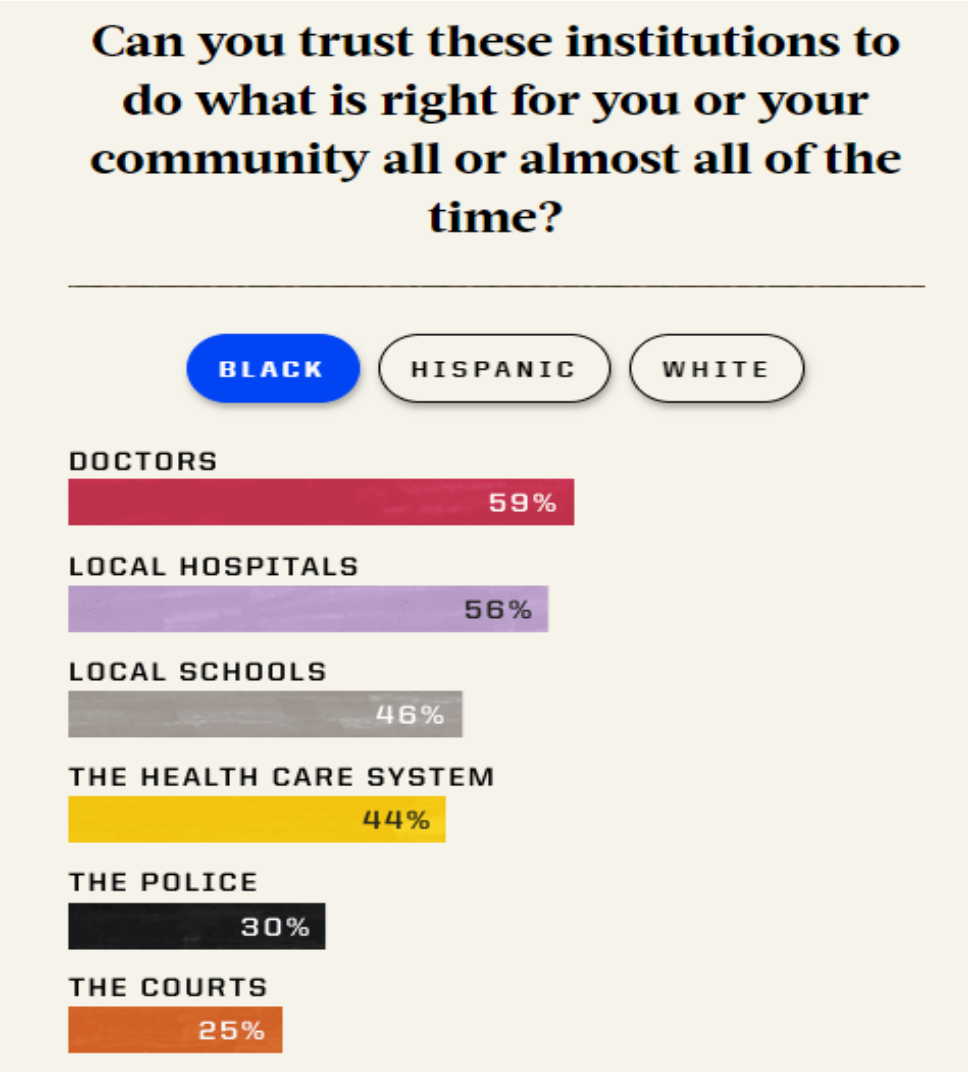
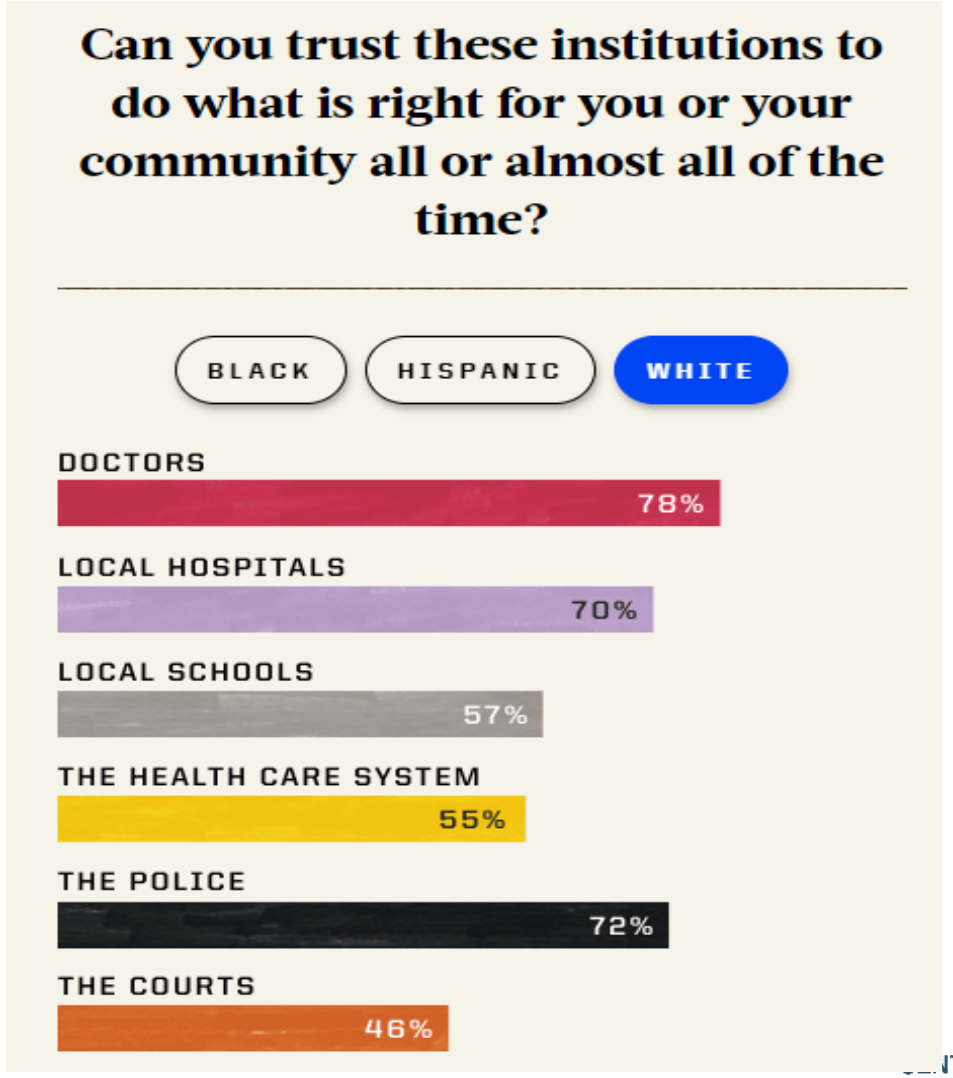
Trust and Trust Worthiness





New poll shows Black Americans see a racist health care system setting the stage for pandemic's impact (https://theundefeated.com/features/new-poll-shows-black-americans-see-a-racist-health-care-system-setting-the-stage-for-pandemics-impact/)

The Hierarchy of Communication Needs

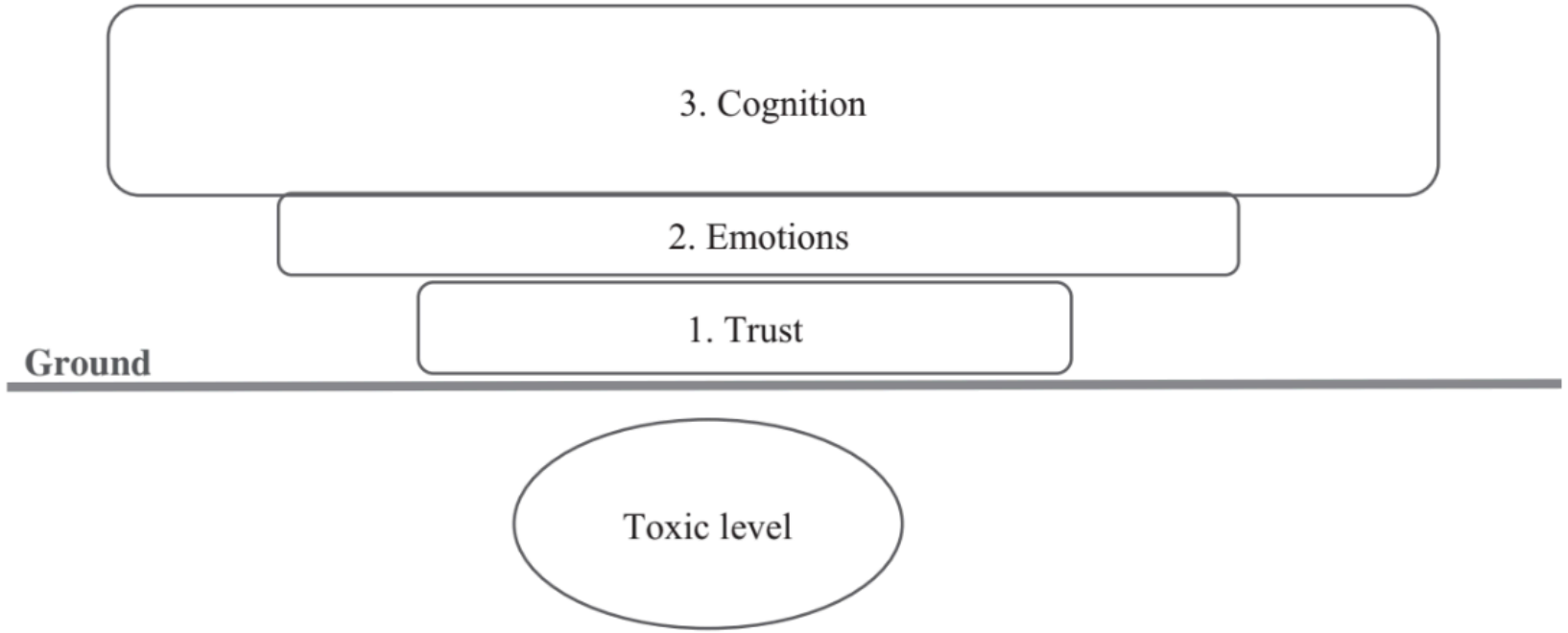
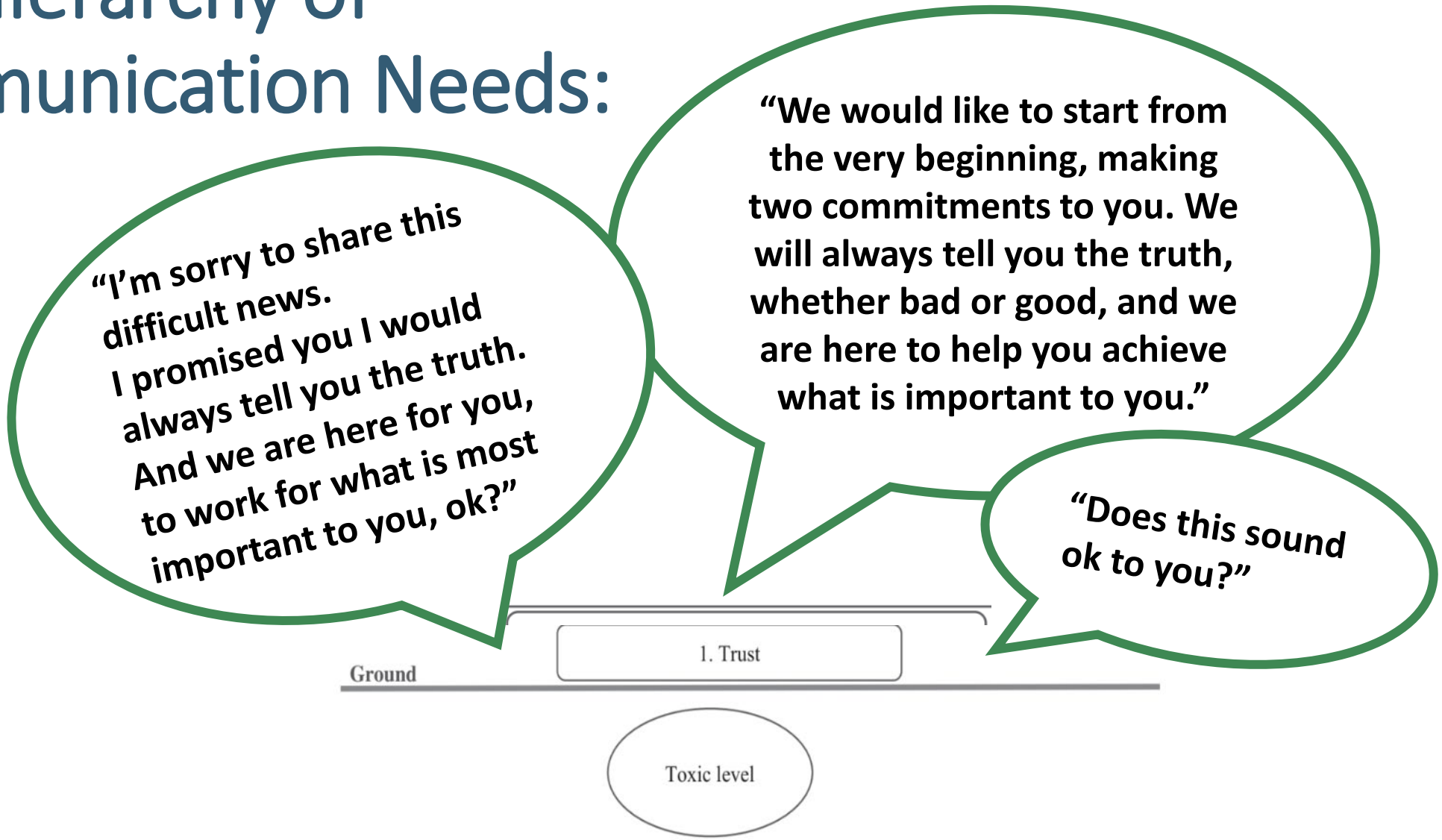


FIG. 1. Hierarchy of communication needs: three levels of complexity in interpersonal communication.

Forte, D. N., Stoltenberg, M., Ribeiro, S. C. D. C., Almeida, I. M. M. O. D., Jackson, V., & Daubman, B. R. (2024). The Hierarchy of Communication Needs: A Novel Communication Strategy for High Mistrust Settings Developed in a Brazilian COVID-ICU. *Palliative Medicine Reports*, *5*(1), 86-93.

The Hierarchy of Communication Needs: Trust



Forte, D. N., Stoltenberg, M., Ribeiro, S. C. D. C., Almeida, I. M. M. O. D., Jackson, V., & Daubman, B. R. (2024). The Hierarchy of Communication Needs: A Novel Communication Strategy for High Mistrust Settings Developed in a Brazilian COVID-ICU. *Palliative Medicine Reports*, *5*(1), 86-93.

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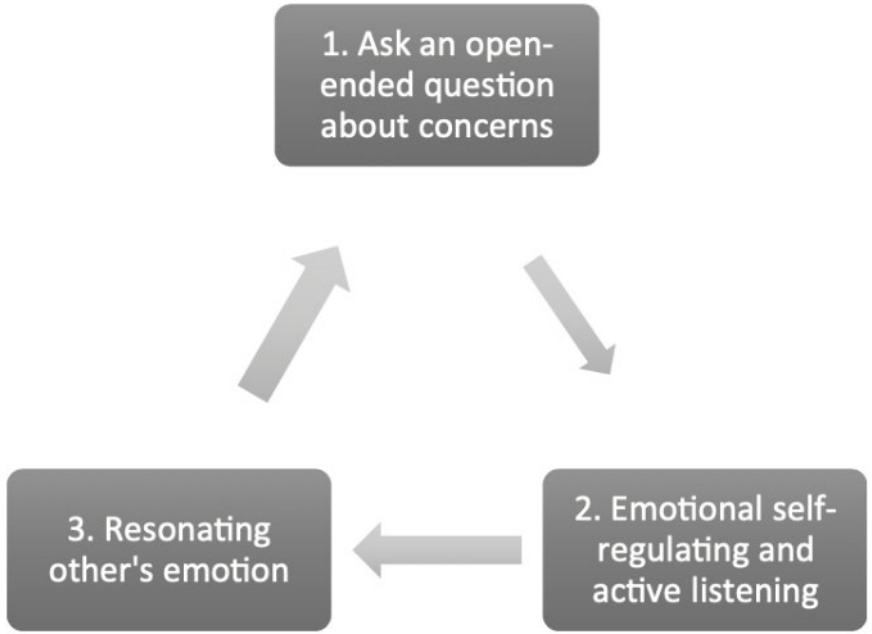
The Hierarchy of Communication Needs: Emotional Resonance



"Could you tell me more about that?"
Or
"And what else worries you?"
Or
And what else are you hoping for?

Forte, D. N., Stoltenberg, M., Ribeiro, S. C. D. C., Almeida, I. M. M. O. D., Jackson, V., & Daubman, B. R. (2024). The Hierarchy of Communication Needs: A Novel Communication Strategy for High Mistrust Settings Developed in a Brazilian COVID-ICU. *Palliative Medicine Reports*, *5*(1), 86-93.

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The Hierarchy of Communication Needs: Cognition

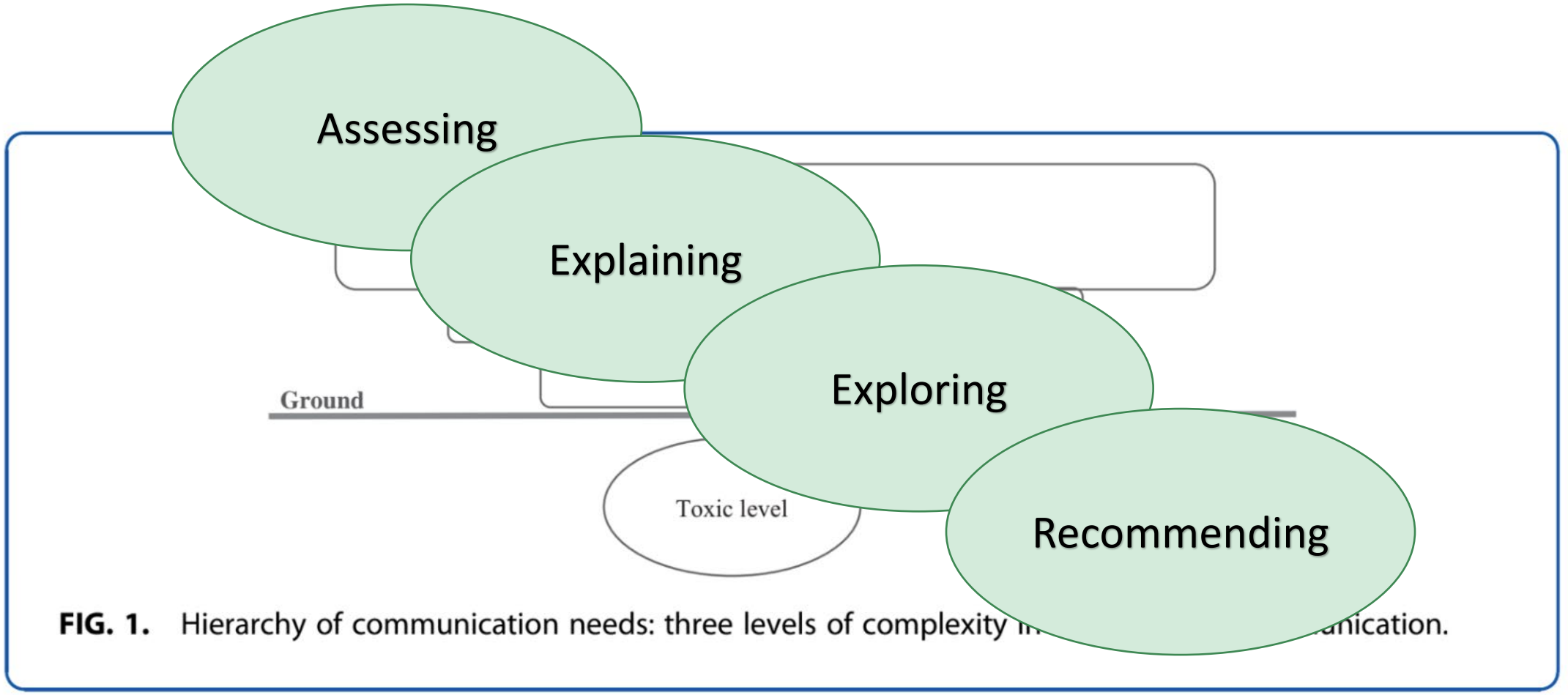

FIG. 1. Hierarchy of communication needs: three levels of complexity in ...unication.

Forte, D. N., Stoltenberg, M., Ribeiro, S. C. D. C., Almeida, I. M. M. O. D., Jackson, V., & Daubman, B. R. (2024). The Hierarchy of Communication Needs: A Novel Communication Strategy for High Mistrust Settings Developed in a Brazilian COVID-ICU. *Palliative Medicine Reports*, *5*(1), 86-93.

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Kleinman's Explanatory Model

- What do you call your problem? What name do you give it?
- What do you think has caused it?
- Why did it start when it did?
- What does your sickness do to your body? How does it work inside you?
- How severe is it? Will it get better soon, or will it take longer?
- What do you fear most about your sickness?
- What are the chief problems your sickness has caused for you (personally, family, work, etc.)?
- What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?

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Kleinman's Explanatory Model (https://www.culturallyconnected.ca/practice/kleinmans-explanatory-model)

Communication Issues

The single biggest problem in communication is the illusion that it has taken place.

-George Bernard Shaw

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MAYO CLINIC

CONCISE REVIEW FOR CLINICIANS

Providing Appropriate End-of-Life Care to Religious and Ethnic Minorities

Daniel K. Partain, MD; Cory Ingram, MD; and Jacob J. Strand, MD

- Elicit the Patient's Explanatory Model of Illness
- Address the Patient's RS Values
- Determine the Patient's Desired Approach to truth-telling
- Understand How the Patient's Family Is Involved in the Care
- Negotiate Cultural Conflicts

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Mayo Clin Proc. 2017;92(1):147-152. doi:10.1016/j.mayocp.2016.08.024

Importance of Religion & Spirituality

When medical teams directed spiritual support and end-of-life conversations to patients with advanced cancer who reported ‘‘a high degree of spiritual support from religious communities,’’ these patients had greater odds of receiving hospice care and lower odds of dying in an ICU when compared to similar patients who did not receive the medical team support.

Balboni et al. JAMA Intern Med 2013;173:1109–1117

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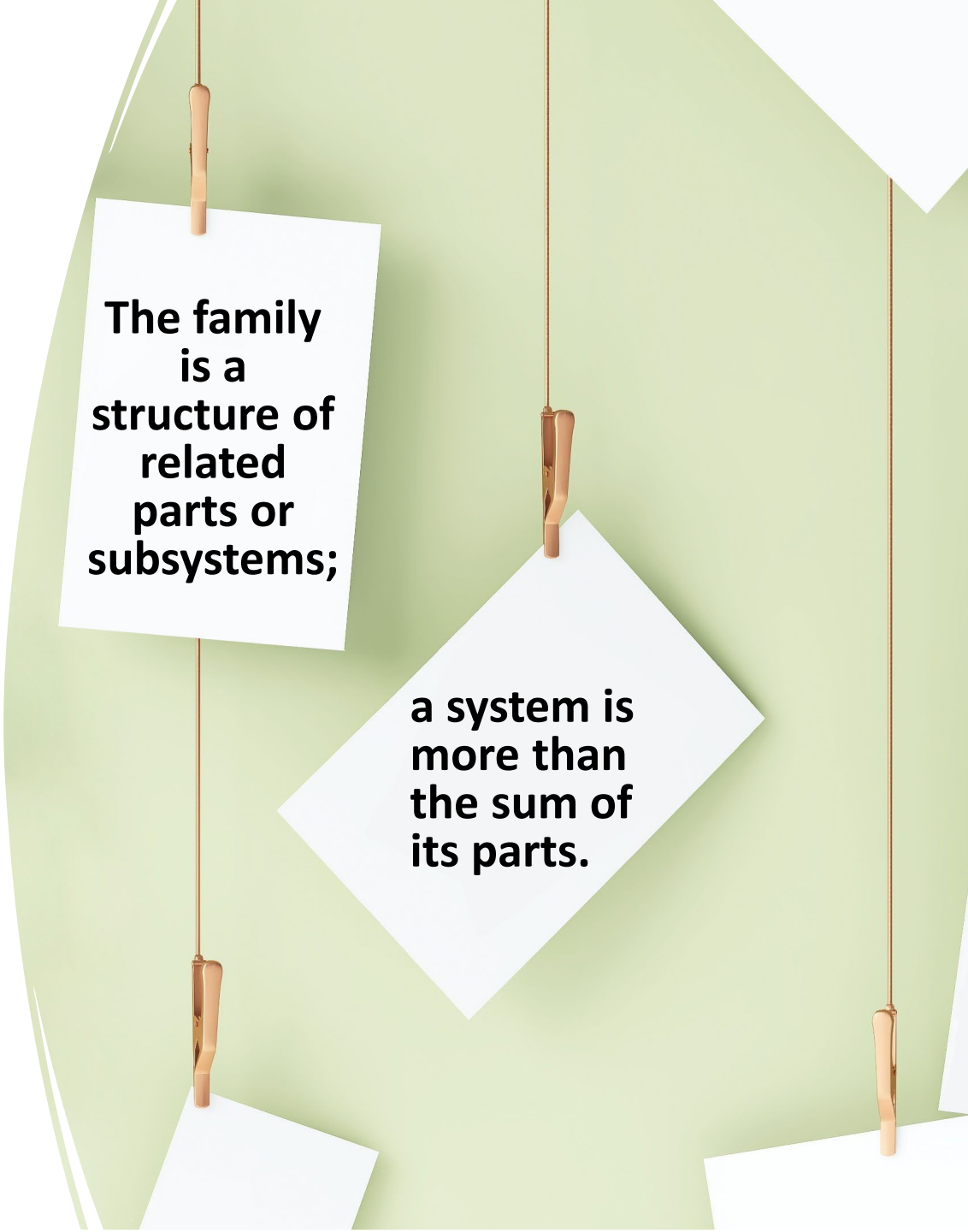
52-year-old man from Mexico with dysuria (continued)

- In U.S. 15 years, lives with cousin, rest of family in Mexico
- Works in a factory, intermittently unable to work
- Undocumented
- No insurance
- Limited English

Family Systems Lens

"Whoever the person says his or her family is. It may include relatives, partners and friends."

Canadian Hospice and Palliative Care Association, 2013



Source: Bemak, F., Chung, R. C. Y., & Pedersen, P. (2003). Counseling refugees: A psychosocial approach to innovative multicultural interventions. Greenwood Pub Group

Family Systems Lens

- Family Roles and Dynamics
    - Patterns of Interaction
        - Reorganization Necessity
- Family Rules and Norms
    - Historical Context
- Boundaries within the Family
    - Subsystems

Family Systems Lens

- Decision-Making and Control
    - Locus of Control
- Life Cycle Considerations
    - Family Life Cycle Stages
        - Disruptions to the Cycle
    - Normative versus non-normative

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Recognizing and Challenging Power Imbalances

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2. Recognizing and Challenging Power Imbalances

- What power imbalances can you identify in this case?
- How would you best challenge them?
- How can you/we connect with this patient?
- What does “Hospitality” mean to you in the context of your practice?

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Interpreters as Cultural Ambassadors in Hospice & Palliative Care

- Interpreters are more than language translators—they are cultural bridges.
- They support emotional, spiritual, and family-centered communication.
- Help convey meaning, not just words—preserving tone, values, and dignity.
- Build trust, navigate cultural beliefs, and strengthen decision-making.
- Essential team members in ensuring culturally respectful end-of-life care.

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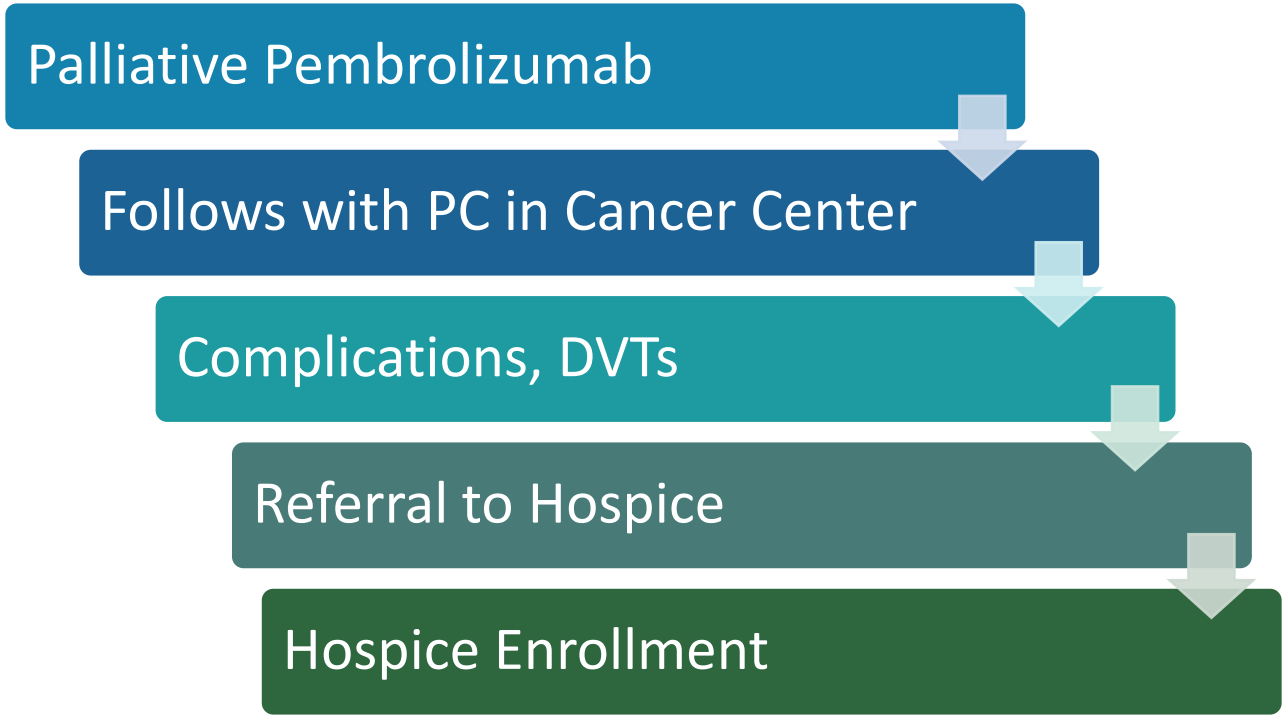
52-year-old man from Mexico with dysuria



Intersectionality

The complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, ageism and classism) combine, overlap, or intersect specially in the experiences of marginalized individuals or groups

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3. Developing Partnerships

- Work with our organizations' health equity programs
- Engage with and learn from community partners and champions
- Increase level of civil engagement

52-year-old man from Mexico with dysuria

- Fatalism
- What matters most?
  - *“I want to go back to Mexico to see my family.”*
- Support system

Desire to Return to Country of Origin

- Patients at end of life often express a desire to travel, and many have requests that go unfulfilled.
- When palliative care teams assist patients with end-of-life travel, they empower them with a greater sense of control over the dying process.
- Medical travel as a goals-of-care comfort measure for the palliative care patient
- Include travel back to the country of origin in the planning of care for terminally ill patients.

Deamant, C. D., Liu, E., Hinami, K., Weinstein, R. A., & Trick, W. E. (2015). From Albania to Zambia: travel back to country of origin as a goal of care for terminally ill patients. Journal of Palliative Medicine, 18(3), 251-258

Aisporna, Cheryl MSN, RN; Erickson-Hurt, Carma DNP, ACHPN. End-of-Life Travel: A Bucket List Desire for Patients With Life-Limiting Illnesses. Journal of Hospice & Palliative Nursing 21(5):p 397-403, October 2019. | DOI: 10.1097/NJH.0000000000000542

“Along with the capacity for mobility, reinvention and resilience required of migrants, there is another side to our world on the move that deserves greater recognition and understanding. Attending to the situation of the migrant at times of illness and death is to open ourselves to the coming together of two of the most radical thresholds of bodily estrangement and vulnerability: the movement across territories and from life to death.”

(Gunaratnam, 2013, p. 216)

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Reflection (continued)

- What matters most to you?
- What would be more meaningful to you if you had a serious illness and were approaching your end of life?

Thank you!

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Questions?

MNCOENewcomerHealth@state.mn.us

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Center of Excellence Reminders!

Subscribe to Center of Excellence in Newcomer Health Updates (https://public.govdelivery.com/accounts/MNMDH/subscriber/new?topic_id=MNMDH_463) for training announcements and other guidance and resources.

Upcoming training opportunities at Trainings: Minnesota Center of Excellence in Newcomer Health (www.health.state.mn.us/communities/rih/coe/webinars.html)

ECHO COLORADO

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Refugee, immigrant and migrant communities face multiple systems barriers that negatively affect health.

Newcomer Health

This ECHO series is designed to increase medical providers' knowledge of the resettlement and health issues of newcomers, including refugee, immigrant and migrant (RIM) populations. It will review resettlement pathways, evidence-based screening recommendations, and more common diagnoses and treatment approaches for pediatric and adult populations.

Sessions include brief didactic presentations by immigrant health experts and discussion of participant-submitted cases. Participants are highly encouraged to submit de-identified patient cases for group discussion and expert consultation.

AUDIENCE

Health care workers across the U.S. who provide care or who want to learn more about providing care for newcomers, including refugees, immigrants and migrants

COMMITMENT

Three monthly ECHO sessions held virtually
Last Tuesday of the month
8:00 AM PT | 9:00 AM MT | 10:00 AM CT | 11:00 AM ET
April 29 - June 24

SESSIONS

APRIL 29	Introduction to Newcomer Health: Clinic Setting
MAY 27	Introduction to Newcomer Health: Hospital Setting
JUNE 24	Introduction to Newcomer Health in a Changing Landscape: Case-based Learning

Peer Mentored Care Collaborative
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Get more info and register HERE

QUESTIONS?
AD Sanchez, ECHO Coordinator
alfredo.sanchez@cuanschutz.edu

Thank You!

Please remember to complete your evaluation

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