Increasing Advocacy for Cultural Minority Groups Needing Palliative Care

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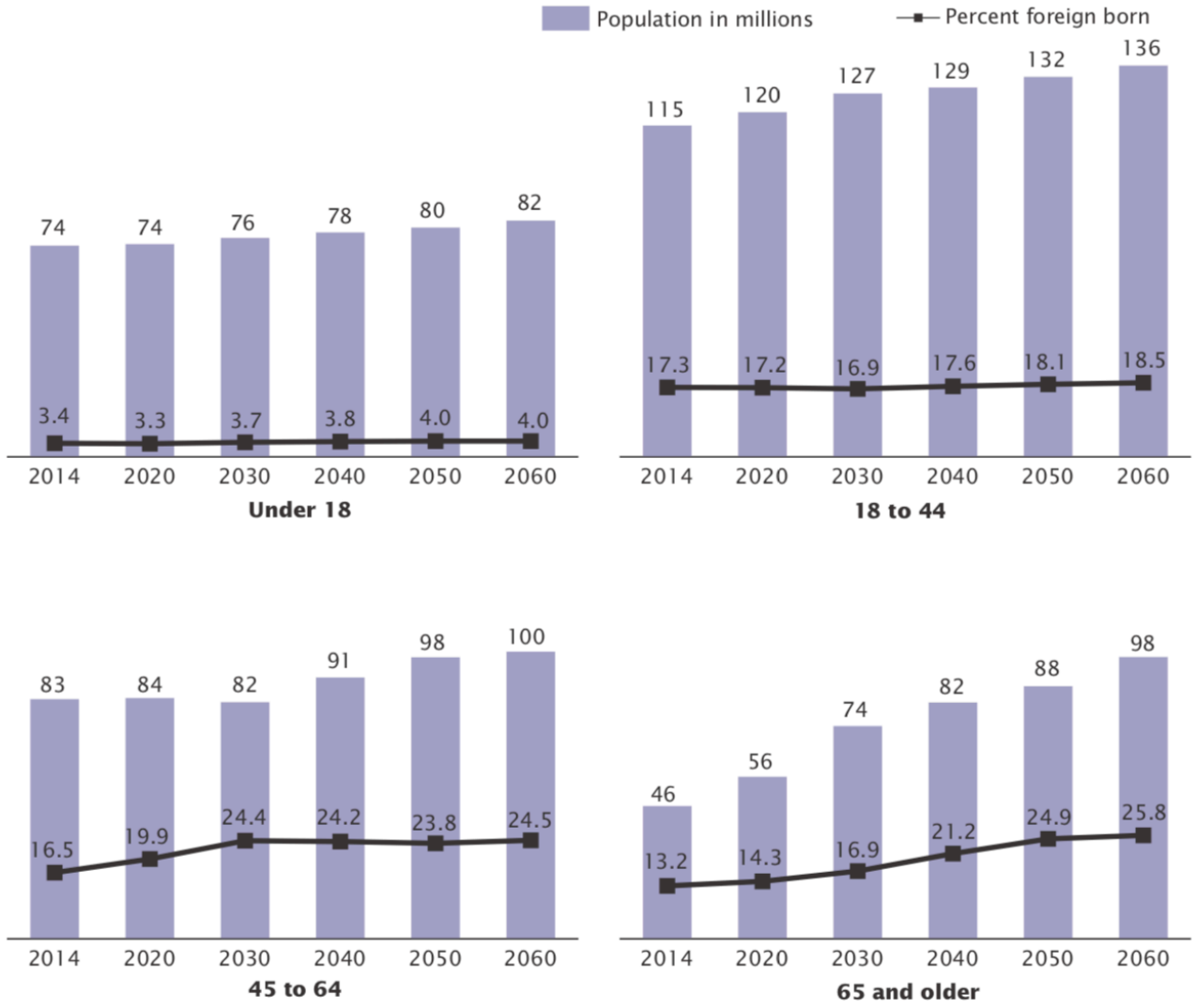
Learning objectives

- Recognize demographic shifts in the populations needing palliative care services
- Consider systemic factors contributing to health disparities
- Identify ways of being an advocate to cultural minority groups in need of palliative care

Figure 5.

Population by Selected Age Group and Nativity: 2014 to 2060



Source: U.S. Census Bureau, 2014 National Projections.

Colby & Ortman (2015).

Disproportionate hospice utilization

Race	Hospice (Medicare)	U.S. Population
Total	1.43M	323.12M
White	86.5%	61.3%
African American	8.3%	13.3%
Latinx	2.1%	17.8%
Asian	1.2%	5.7%
Native American	0.4%	1.3%
Other	1.0%	--
Unknown	0.4%	--
Two or more races	--	2.6%

National Hospice and Palliative Care Organization (2017)
U.S. Census.

Disparity in hospice & palliative care

- 10% LGBT people had EOL discussions with their PCP
- Transgender people were 50-70% less likely than their LGB counterparts to have a will, a living will, or to have appointed a healthcare proxy
- Undocumented immigrants (11.2M) are the largest demographic group explicitly excluded from ACA or Medicare Hospice Benefit

Kcomt & Gorey (2017)
Gray et al. (2017)

Disease affects groups of people differently based on various aspects of diversity.

Why?

What promotes the perpetuation of health disparity?

Health disparities

"A particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have ***systematically experienced greater obstacles*** to health based on… characteristics historically linked to discrimination or exclusion"

~ Health People 2020

Take a few moments to consider…

- What dimensions of your identity are important to you?
  - Ex: Age, disability, religion, ethnicity, SES, sexuality, heritage, national origin, gender, and etc.
- Reflect on the following questions to yourself:
  - Which aspects were easiest to identify? Most difficult?
  - To what degree are parts of your identity stigmatized?

Now consider…

- Which aspects of identity are stigmatized today?
- Now go back 55yrs – 1963 – same aspects still stigmatized? More? Less?
- Now go back 75yrs – 1943 – has anything changed?

How do time periods affect stigma and access to resources?

Aspects of identity

Privilege, Disenfranchisement, and Resiliency

Crenshaw (1989)
Viruell-Fuentes, Miranda, & Abdulrahim (2012)

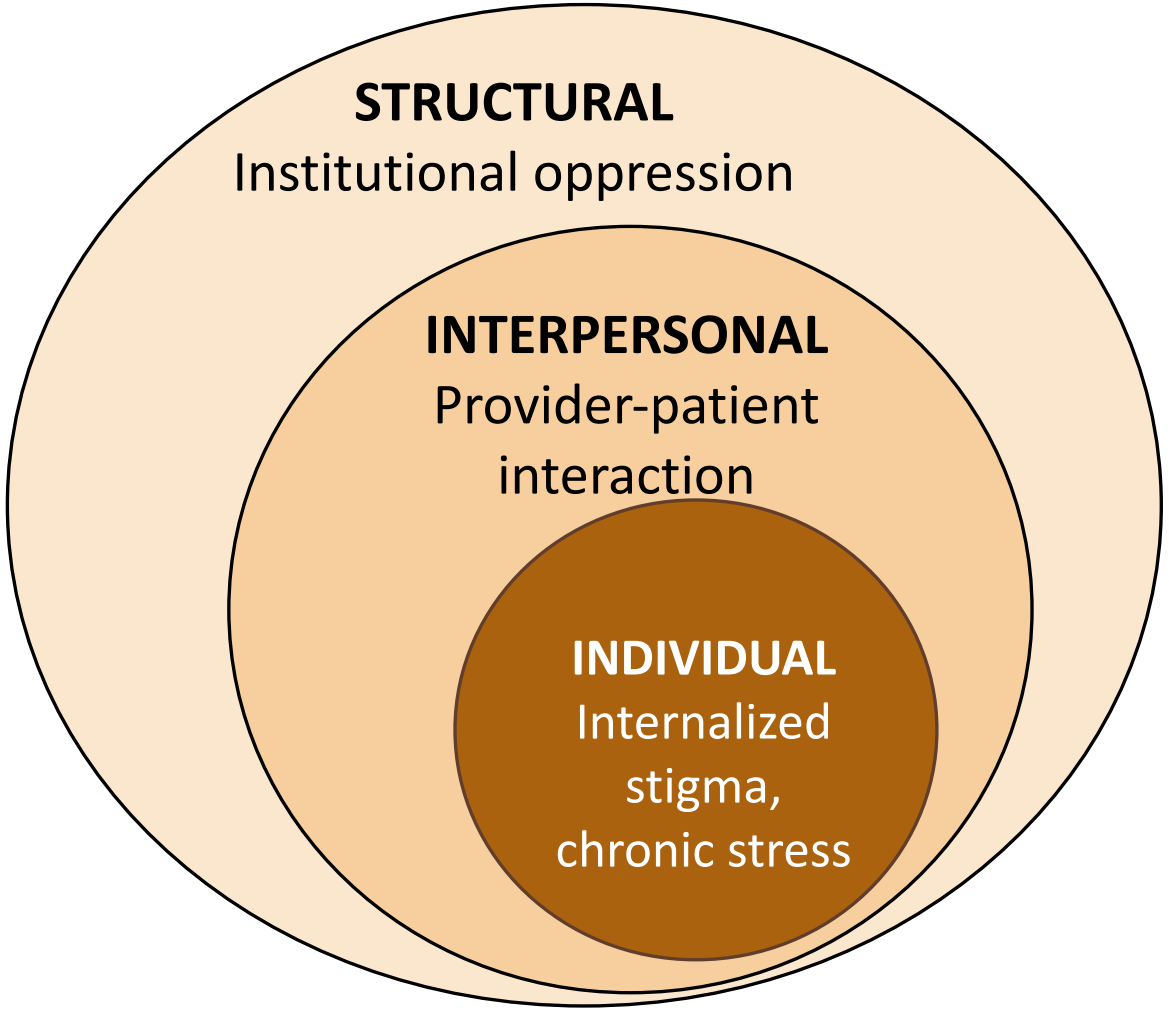
Fundamental cause theory

"Fundamental cause theory proposes that some social factors or circumstances remain persistently associated with health ***inequalities over time*** despite dramatic changes in diseases, risk factors, and health interventions."

- Hatzenbuehler et al. (2013)

Stigma as a fundamental cause

Stigma is “the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised.”

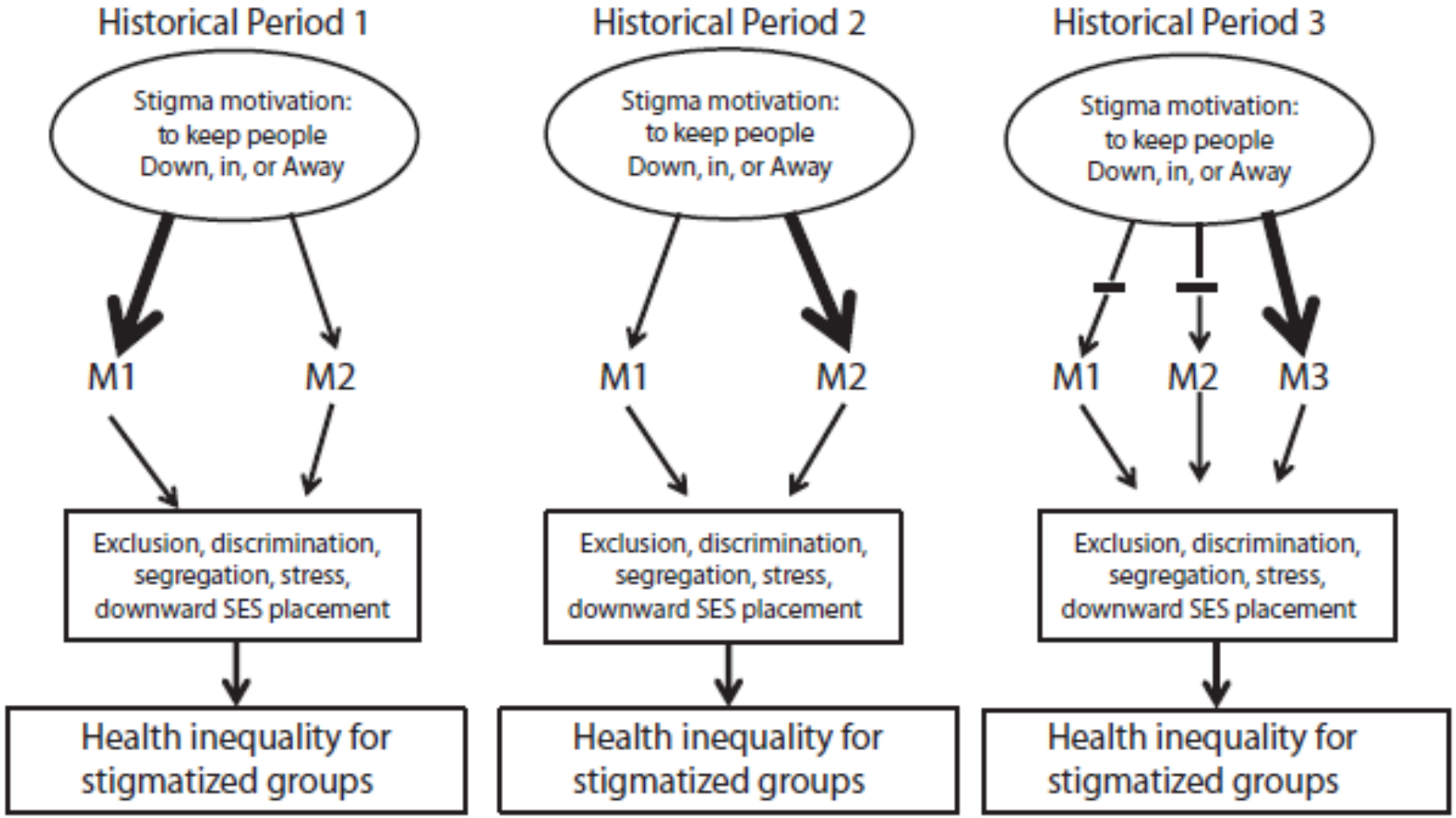


Hatzenbuehler, Phelan, & Link (2013)
Metzl & Hansen (2014)

Reproduction of health inequality

- Keeping down (exploitation)
- Keeping in (social norms)
- Keeping away (avoidance)

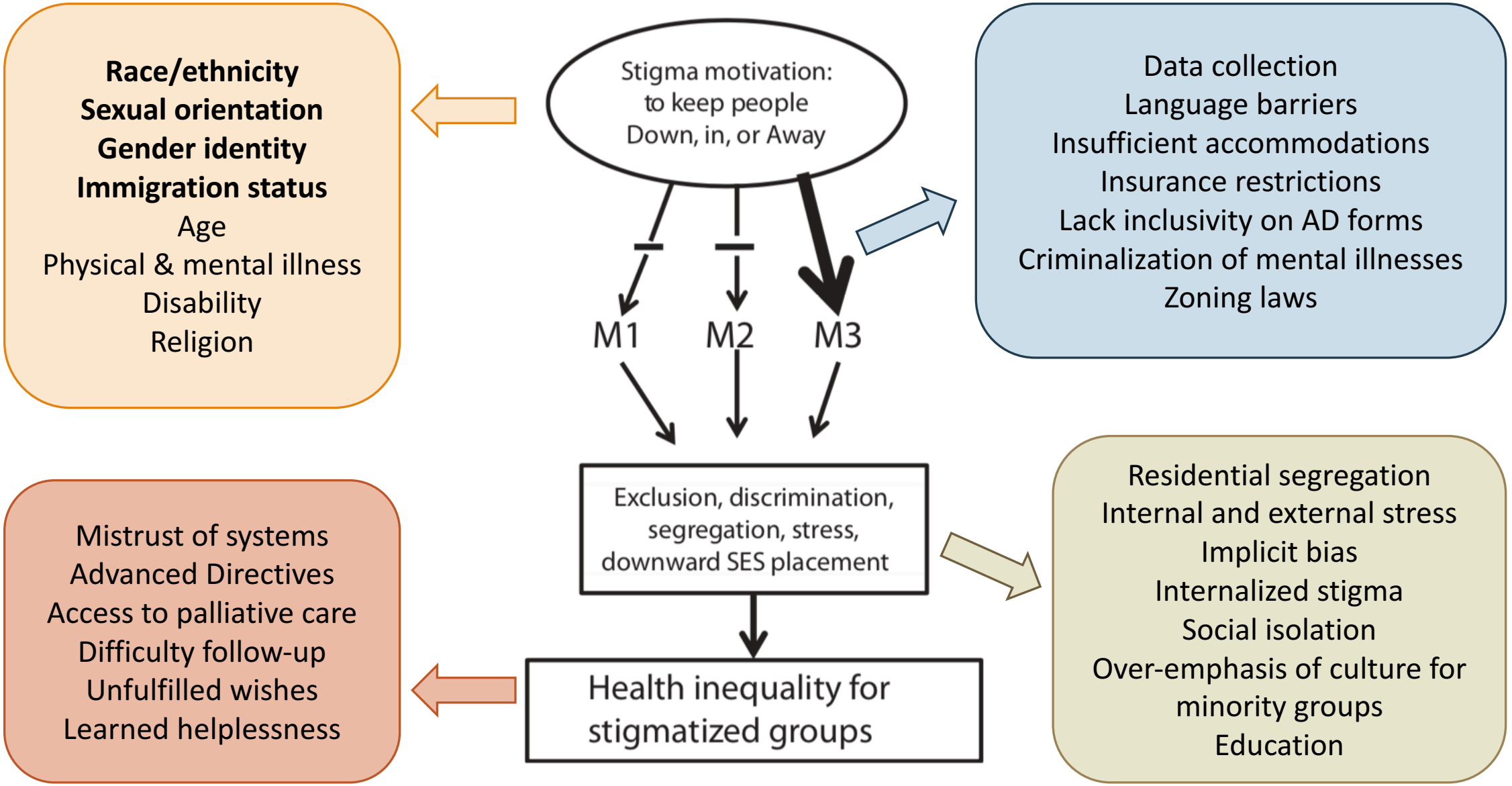
Hatzenbuehler, Phelan, & Link (2013)

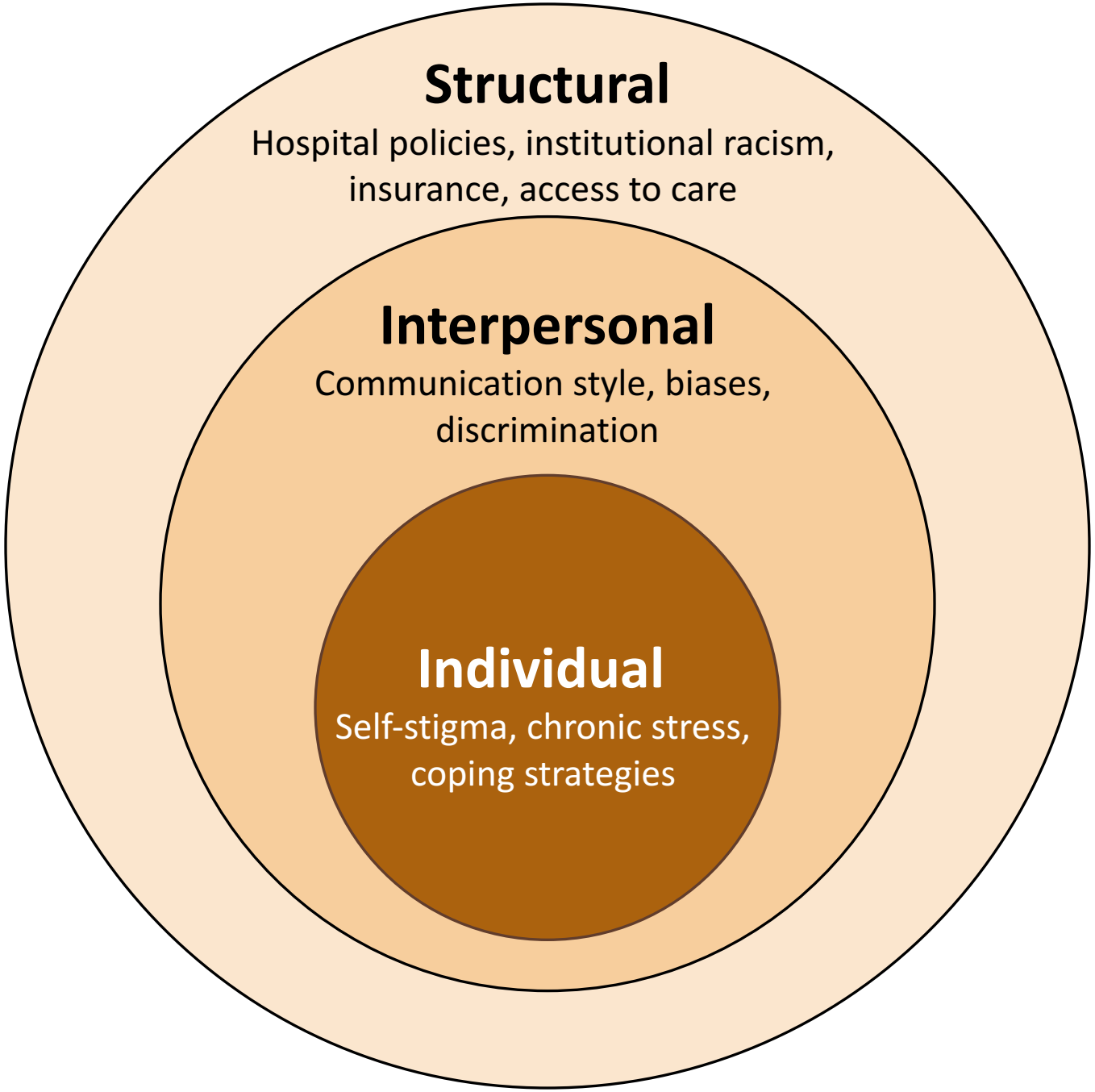


Note. M = mediating mechanism; SES = socioeconomic status. The thick arrow indicates a strong effect whereas the thin arrow indicates a weak effect. The arrow interrupted with a dash indicates a blocked mechanism.

FIGURE 1—Multiple mediating mechanisms reproduce disadvantage for stigmatized groups.

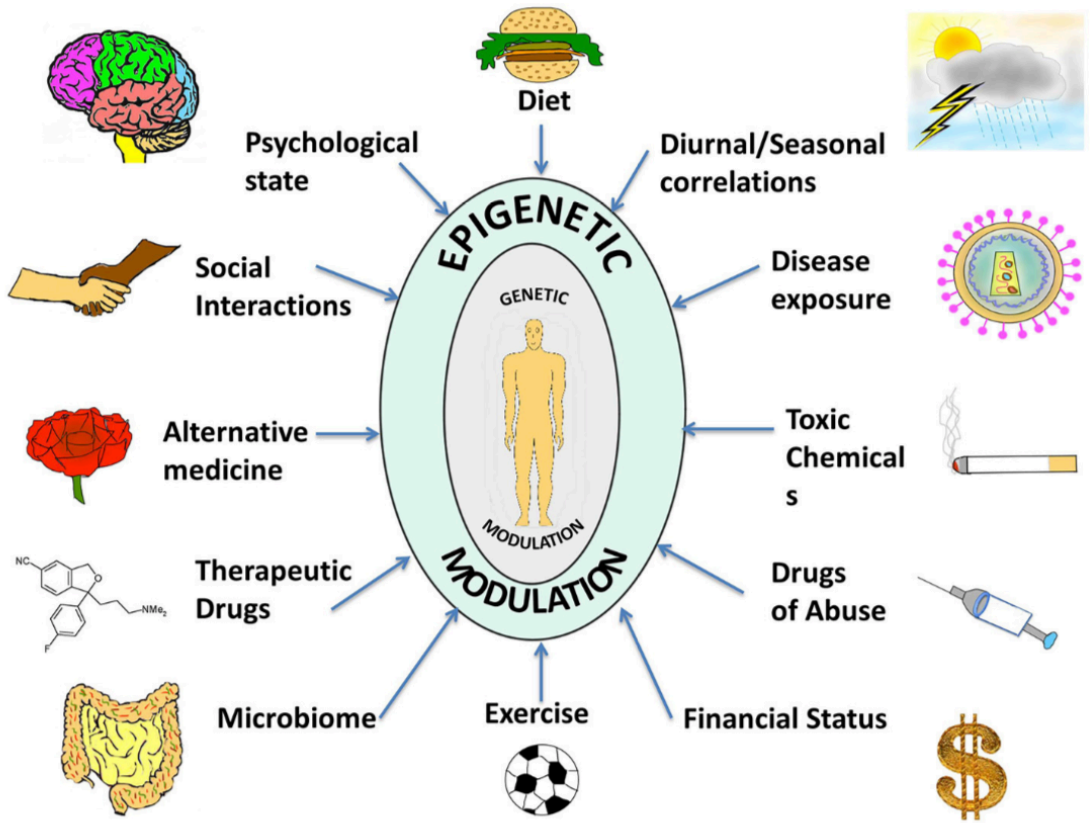
Hatzenbuehler, Phelan, & Link (2013)


Race/ethnicity
Sexual orientation
Gender identity
Immigration status
Age
Physical & mental illness
Disability
Religion
Stigma motivation:
to keep people
Down, in, or Away
M1
M2
M3
Data collection
Language barriers
Insufficient accommodations
Insurance restrictions
Lack inclusivity on AD forms
Criminalization of mental illnesses
Zoning laws
Exclusion, discrimination,
segregation, stress,
downward SES placement
Residential segregation
Internal and external stress
Implicit bias
Internalized stigma
Social isolation
Over-emphasis of culture for
minority groups
Education
Health inequality for
stigmatized groups
Mistrust of systems
Advanced Directives
Access to palliative care
Difficulty follow-up
Unfulfilled wishes
Learned helplessness

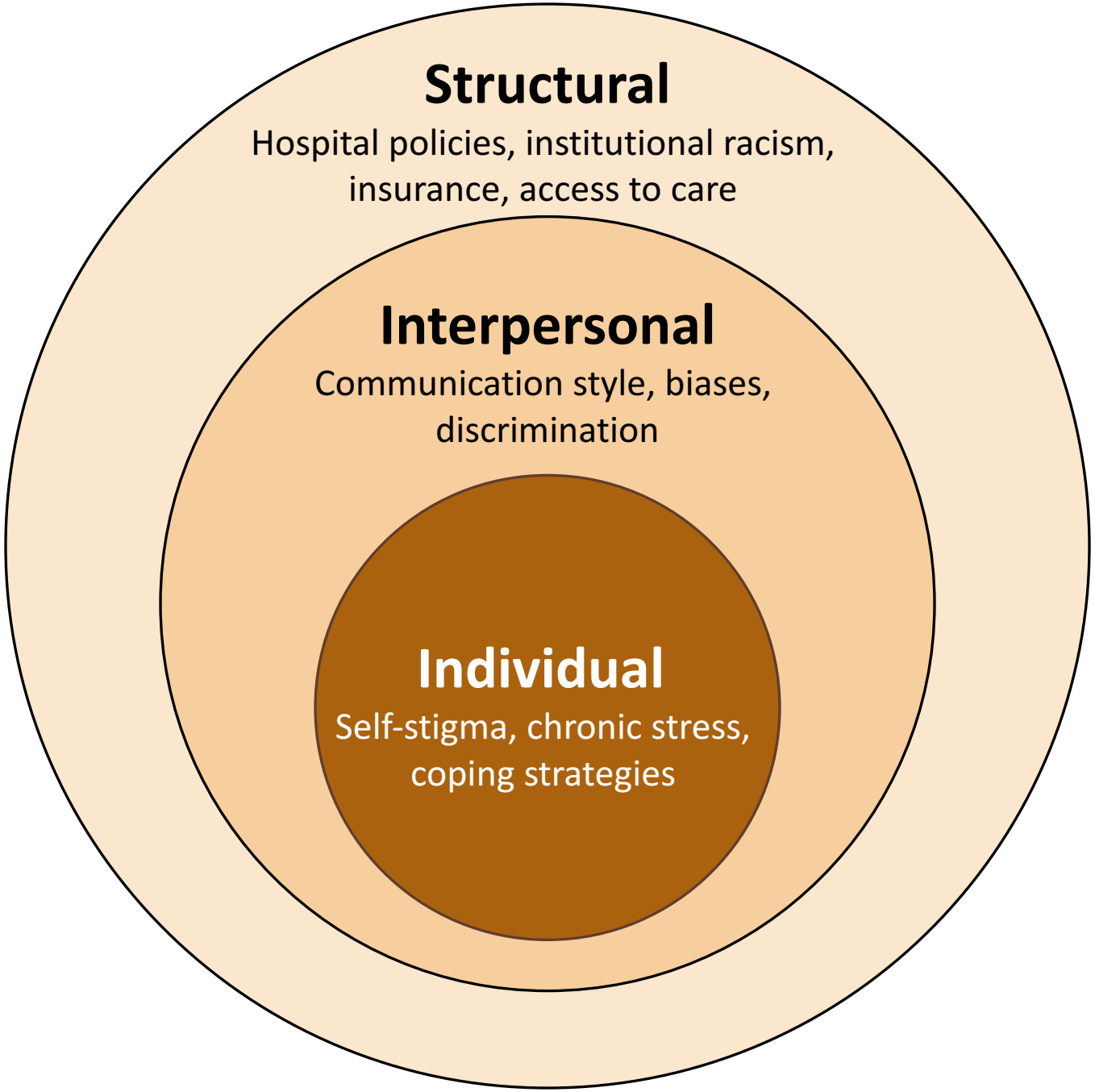

Structural
Hospital policies, institutional racism, insurance, access to care
Interpersonal
Communication style, biases, discrimination
Individual
Self-stigma, chronic stress, coping strategies

Structural factors beyond healthcare

- Epigenetics
- Access to care
- Infrastructure
- Adaptation and agency



Smith & Barley (2014)
Kanherkar et al. (2014)


Structural
Hospital policies, institutional racism, insurance, access to care
Interpersonal
Communication style, biases, discrimination
Individual
Self-stigma, chronic stress, coping strategies

Race/Ethnicity

Humans of New York
5 hrs ·

“We decided to raise our son here (Ghana). Because he’d never have to think about the color of his skin. We never have to explain what it means to be black. Or the rules of being black… It’s exhausting to be conscious of your skin all the time. You either become militant or you become defeated.”

(Accra, Ghana)

Effects of stigma

- Structural level
  - Institutional racism in treatment and services
  - Unequal access to care and information
- Interpersonal level
  - Mistrust of institutions
  - Communication
- Individual level
  - Stereotype threat
  - Health effects of chronic stress

Karikari-Martin, P., McCann, J. J., Farran, C. J., Hebert, L. E., Haffer, S. C., & Phillips, M. (2016)
Cruz-Oliver, D. M., Talamantes, M., & Sanchez-Reilly, S. (2014).

EOL Planning

- Structural level
  - Less likely to have ADs or use hospice benefits
- Interpersonal level
  - Mistrust
  - Cultural broker
- Individual level
  - Cultural and familial preferences
  - Acculturation level

Karikari-Martin, P., McCann, J. J., Farran, C. J., Hebert, L. E., Haffer, S. C., & Phillips, M. (2016)
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LGBTQ+ Populations

Watershed Moments in History: LGB Communities

1924: Society for Human Rights founded – first documented gay rights organization
1952: DSM pathologizes homosexuality (removed 1973)
1953: Eisenhower's EO bans homosexuals from federal employment
1969: Stonewall Inn riots
1970: First Gay Pride parade
1975: First federal gay rights bill proposed
1979: March on Washington for LGBT rights
1981: Gay-Related Immune Deficiency (later termed HIV)
1988: First World AIDS Day
1993: Don't Ask Don't Tell (Clinton); repealed 2011 (Obama)
1995: Hate Crimes Sentencing Enhancement Act
1996: DoMA signed by Clinton
2000: VT first state to legalize civil unions b/w same-sex couples
2008: CA Proposition 8 approved – same-sex marriage illegal (unconst'l 2010)
2009: Matthew Shepard & James Byrd Jr Hate Crimes Prevention Act (Obama)
2012: Obama first sitting president to publically support LGBT right to marriage
2015: Military Equal Opportunity policy includes gay/lesbian military members
Supreme Court legalizes same-sex marriage
2016: Eric Fanning first openly gay Secretary of the Army
First national monument to LGBT rights (Obama)
2017: Trump removes White House LGBT webpage

Watershed Moments in History: Transgender Community

1952: First American (Army Veteran) to receive sex reassignment
1966: Compton Cafeteria Riots
1972: Sweden legalizes gender reassignment
1975: Minneapolis: the first to prohibit trans discrimination; MN signs state law 1993
1987: DSM adds GID; changed to Gender Dysphoria 2013
1992: First International Conference on Transgender Law & Employment Policy
1999: Soldier murdered by other soldiers for being in a relationship w/transwoman
First Transgender Day of Remembrance
2003: National Center for Transgender Equality
2004: First Trans March (San Francisco)
2005: CA first state to mandate transgender health care coverage
2009: First openly transperson a Presidential appointee (Obama)
2010: Employment protections cover Trans federal employees
2011: OPM issues guidance for supporting transgender employees
2012: EEOC declares transgender employees protected
2014: Medicare required to cover sex reassignment surgery
Civil Rights Act of 1964 now includes gender identity (including transgender)
2015: Obama mentions transgender people in State of the Union address
First openly transgender person hired onto President Obama's staff
2016: Transgender people allowed to openly serve in US Military
2017-present: Uncertain future for trans-identified military service members

Effects of Stigma

- Structural level
  - Less likely to have employer health benefits than hetero peers
  - Few support groups specific to LGBT populations
  - Legal rights at EOL, policy favors biological family over family of choice
- Interpersonal
  - h/o abuse, discrimination, concealing identity
  - Providers' knowledge of needs unique to LGBT populations
- Individual level
  - Hetero-normative, cis-normative society
  - Poor coping, increased chronic stress, increased morbidity/mortality
  - Increased risk for mental health problems

(Lawton, White, & Fromme, 2015; Harding, Epiphaniou, & Chidgey-Clark, 2012; Hughes & Cartwright, 2014, 2015; Stinchcombe, Smallbone, Wilson, & Kortes-Miller, 2017

Preparing for EOL care

- Structural level:
  - Access to care resources (e.g., knowledge of AD, living wills, etc.)
  - LGBT-friendly care environments
- Interpersonal level:
  - Fear of disclosing aspects of identity
  - Identify family of choice as surrogates
  - Respecting AD and EOL wishes
- Individual level:
  - Avoidance of medical institutions
  - Poorer medical/mental health in high stigma environments

(Lawton, White, & Fromme, 2015; Harding, Epiphaniou, & Chidgey-Clark, 2012; Hughes & Cartwright, 2014, 2015; Stinchcombe, Smallbone, Wilson, & Kortes-Miller, 2017)

Partner and family involvement

- Social support: “lavender families”, “families of choice”
- Interpersonal dynamics
  - Reuniting/reconciling with family of origin, estranging family of choice
- Disenfranchised grief of partner
  - Limit the partner’s ability to grieve openly
  - Limited bereavement support from health care professionals
  - Feelings of isolation

Unauthorized immigrants

Effects of stigma

- Structural
  - Language, education
  - Immigration policy, excluded from Medicare
  - Risking life and death for medical care
  - Access to resources (e.g., language line, spiritual care, cultural broker)
- Interpersonal
  - Cultural awareness, communication style, language barriers
  - Trust of institutions/providers
- Individual
  - Health literacy, internalized stigma
  - Effect of chronic stress on health and coping resources

(Cervantes, Fischer, Berlinger, Zavalaga, Camacho, Linas, & Ortega, 2017; Jaramillo & Hui, 2016; Metchnikoff, Naughton, & Periyakoil,, 2018; Smith, Sudor, & Perez-Stable, 2009)

Communication

- Assess language proficiency and preference
  - “What language do you speak at home?”
- Use simple language (avoid jargon)
- Assess prior knowledge
  - “What do you already know about your illness?”
- Encourage asking questions
  - “What questions do you have?”
- Used closed-loop communication
  - If possible, use professional interpreter (not family)

Adapted from Smith, Sudore, & Perez-Stable 2009

How to be an ally

- Express interest in their culture
  - “What about your culture is important for me to know?”
  - Learn about traditional cultural concepts/values
- Express interest in their culture’s medical practice
  - “How do doctors in your culture talk with people about illness?”
- Inquire about their social support
- Be vigilant for signs of mistrust or fear

Adapted from Smith, Sudore, & Perez-Stable 2009

Recommendations

Broaden conceptualization of “culture”

- Beyond the values of different groups
- Recognize the complex cultural structures that produce inequalities and create barriers to inclusion
- Understand the historical context how culture manifested

Metzl & Hansen (2014)

Addressing stigma in the workplace

- What are some microaggressions that you may have overheard in the workplace?
- How might you react or intervene when you hear a microaggression being directed to someone?

Self-reflective questions

- How do you think patients see you?
- How do you know if there's a cultural issue in the room? What do you do?
- How do you create a safe space?
- How do we maintain compassion working with difficult patients?

Have I "ASKED" Myself the Right Questions?

- ***A****wareness*: Am I aware of my personal biases and assumptions about various cultural groups?
- ***S****ensitivity*: Am I remaining culturally sensitive and practicing cultural humility when taking a patient's history?
- ***K****nowledge*: Do I have knowledge of the patient's understanding of their dx, prognosis, and if/how their cultural identity contributes to their understanding?
- ***E****xperience*: What is my experience with my patient's cultural groups? Do these experiences help me provide culturally sensitive tx and if so, how?
- ***D****uration*: How much time do I have with the patient and is this the time to ask about their cultural identity?

Adapted from Transcultural C.A.R.E. Associates.

Questions for patients

- What is it like for you to work with someone who looks like me?
- What is your experience with healthcare providers in the past? Do you feel your concerns have been addressed?
- How did you feel when you learned about you dx?
- What matters most in your treatment?
- Is there anything I should know about you that would be important in your care?

Thank you

Questions?

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