Cultural Aspects at the End of Life

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City of Hope - End of Life Symposium

Disclosures

I do not have anything to disclose.

Cultural Competency

TABLE 1.1

ADDRESSING Cultural Influences

Cultural influence	Dominant group	Nondominant or minority group
Age and generational influences	Young and middle-aged adults	Children, older adults
Developmental or other Disability[a]	Nondisabled people	People with cognitive, intellectual, sensory, physical, and psychiatric disabilities
Religion and spiritual orientation	Christian and secular	Muslims, Jews, Hindus, Buddhists, and other religions
Ethnic and racial identity	European Americans	Asian, South Asian, Latino, Pacific Islander, African, Arab, African American, Middle Eastern, and multiracial people
Socioeconomic status	Upper and middle class	People of lower status by occupation, education, income, or inner city or rural habitat
Sexual orientation	Heterosexuals	People who identify as gay, lesbian, or bisexual
Indigenous heritage	European Americans	American Indians, Inuit, Alaska Natives, Métis, Native Hawaiians, New Zealand Māori, Aboriginal Australians
National origin	U.S.-born Americans	Immigrants, refugees, and international students
Gender	Men	Women and people who identify as transgender

Note. Adapted from *Addressing Cultural Complexities in Practice, Second Edition: Assessment, Diagnosis, and Therapy* (p. 18), by P. A. Hays, 2008, Washington, DC: American Psychological Association. Copyright 2008 by the American Psychological Association.
[a]With the increased use of the term *intellectual disability*, the term *developmental disability* is being used less often, particularly within the Disability community; however, it is included in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM–5)* and the *International Classification of Diseases, Tenth Edition, Clinical Modification (ICD–10–CM;* see Chapter 4).

Hays, P. A. (2016). The new reality: Diversity and complexity. In P. A. Hays, *Addressing cultural complexities in practice: Assessment, diagnosis, and therapy* (pp. 3–18). American Psychological Association. https://doi.org/10.1037/14801-001

Cultural Humility

In no way are we discounting the value of knowing as much as possible about the health care practices of the communities we serve. Rather, it is imperative that there be a simultaneous process of self-reflection (realistic and ongoing self-appraisal) and commitment to a lifelong learning process. In this way, trainees are ideally flexible and humble enough to let go of the false sense of security that stereotyping brings. They are flexible and humble enough to assess anew the cultural dimensions of the experiences of each patient. And finally, they are flexible and humble enough *to say that they do not know when they truly do not know* and to search for and access resources that might enhance immeasurably the care of the patient as well as their future clinical practice.

	Relevant Information	Questions and Strategies
Attitudes of patients and families	What attitudes do this ethnic group in general, and the patient and family in particular, have toward truth telling about diagnosis and prognosis?	Educate yourself about attitudes common to the ethnic groups most frequently seen in your practice. Determine attitudes of your patient and your patient's family. For example, what is the symbolic meaning of the particular disease?
Beliefs	What are the patient's and family's religious and spiritual beliefs, especially those relating to the meaning of death, the afterlife, and the possibility of miracles?	Acknowledge that spirituality and religion sustain many people during times of distress. Ask questions such as "What is important for us to know about your faith or spiritual needs?" "How can we support your needs and practices?" Where do you find your strength to make sense of this experience?"
Context	Questions about the historical and political context of their lives, including place of birth, refugee or immigration status, poverty, experience with discrimination or lack of access to care, languages spoken, and degree of integration within their ethnic community.	Religious and community organizations may be able to provide general information about the relevant group. Ascertain specific information by asking the following: "Where were you born and raised?" "When did you immigrate to [country], and what has been your experience coming to a new country?" "How has your life changed?" "What language would you feel most comfortable speaking to discuss your health concerns?" "What were other important times in your life and how might these experiences help us to understand your situation?"
Decision-making style	What decision-making styles are held by the group in general and by the patient and family in particular? Is the emphasis on the individual patient making his or her own decisions or is the approach family centered?	Learn about the dominant ethnic groups in your practice: How are decisions made in this cultural group? Who is the head of the household? Does this family adhere to traditional and cultural guidelines?
Environment	What resources are available to aid the effort to interpret the significance of cultural dimensions of the case, including translators, health care workers from the same community or religious leaders, and family members?	Identify religious and community organizations associated with the ethnic groups common in your practice (hospital social worker and chaplains may be able to help you in this effort).

Structural Competency

SOCIAL STRUCTURES: Policies, economic systems, and other institutions that maintain modern social inequities as well as health disparities

STRUCTURAL COMPETENCY: A framework for exploring the effect of such structures on health outcomes
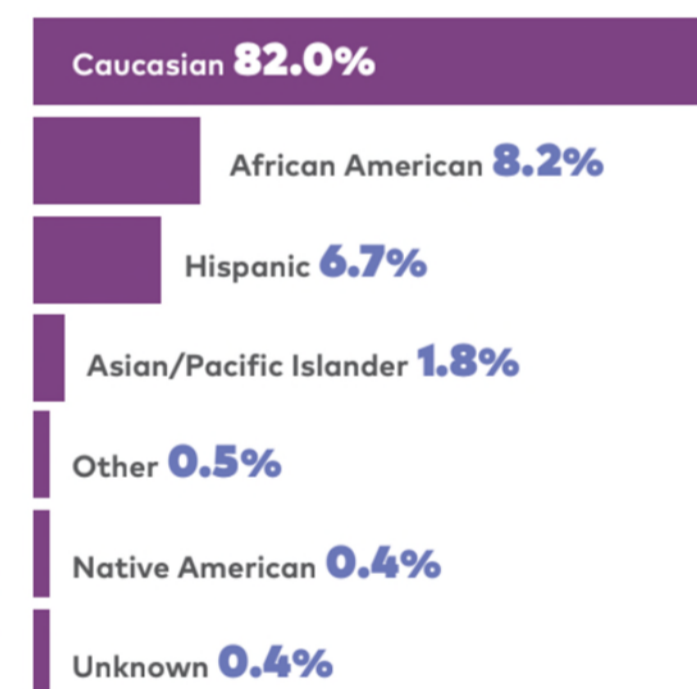
Unjust Disparities or Value Differences?

Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2018?
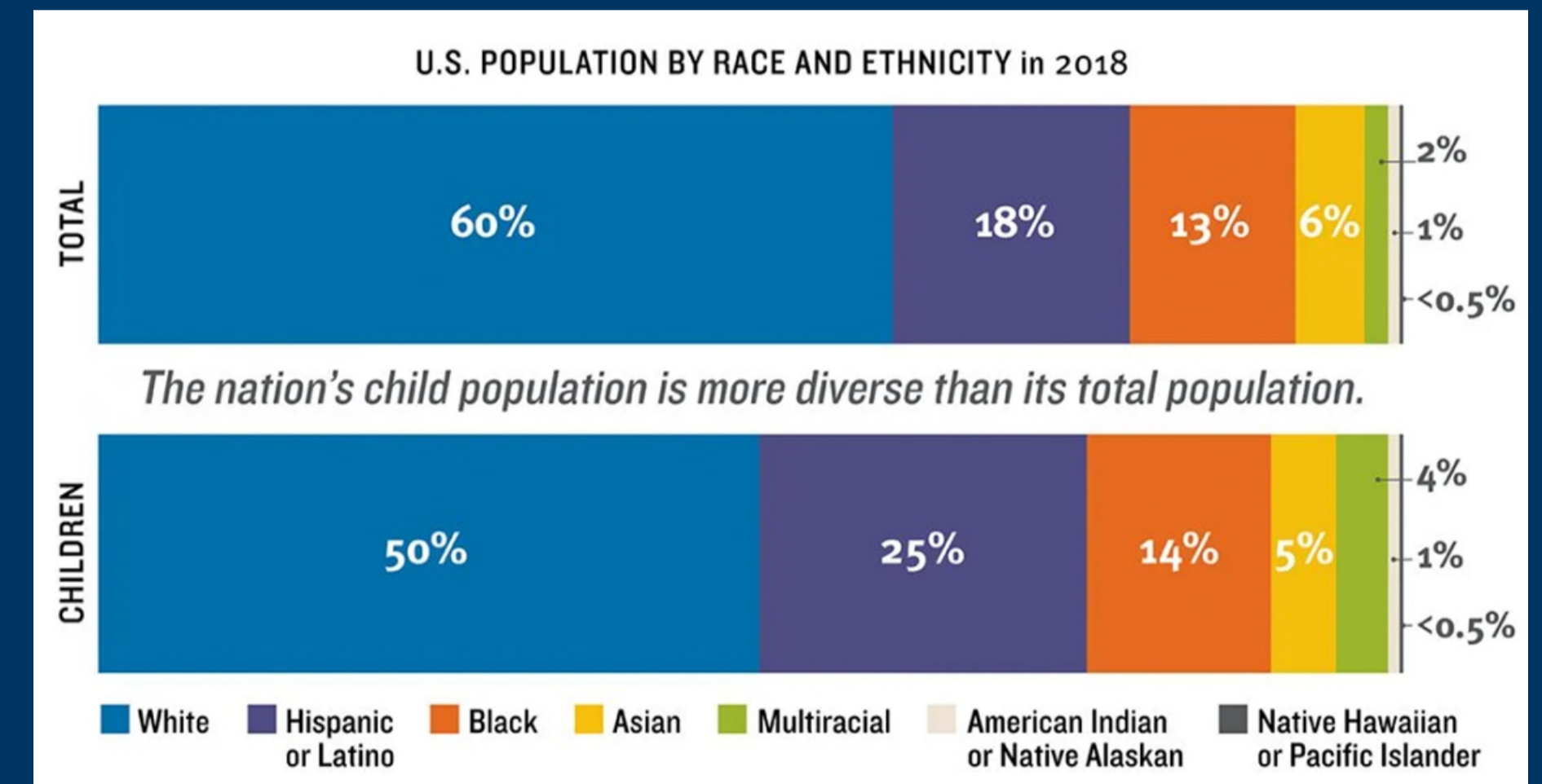
Patient Race

In 2018 a substantial majority of Medicare hospice patients were Caucasian. However, since 2014, patients identified as Asian/Pacific Islander and Hispanic have increased by 45% and 33% respectively.
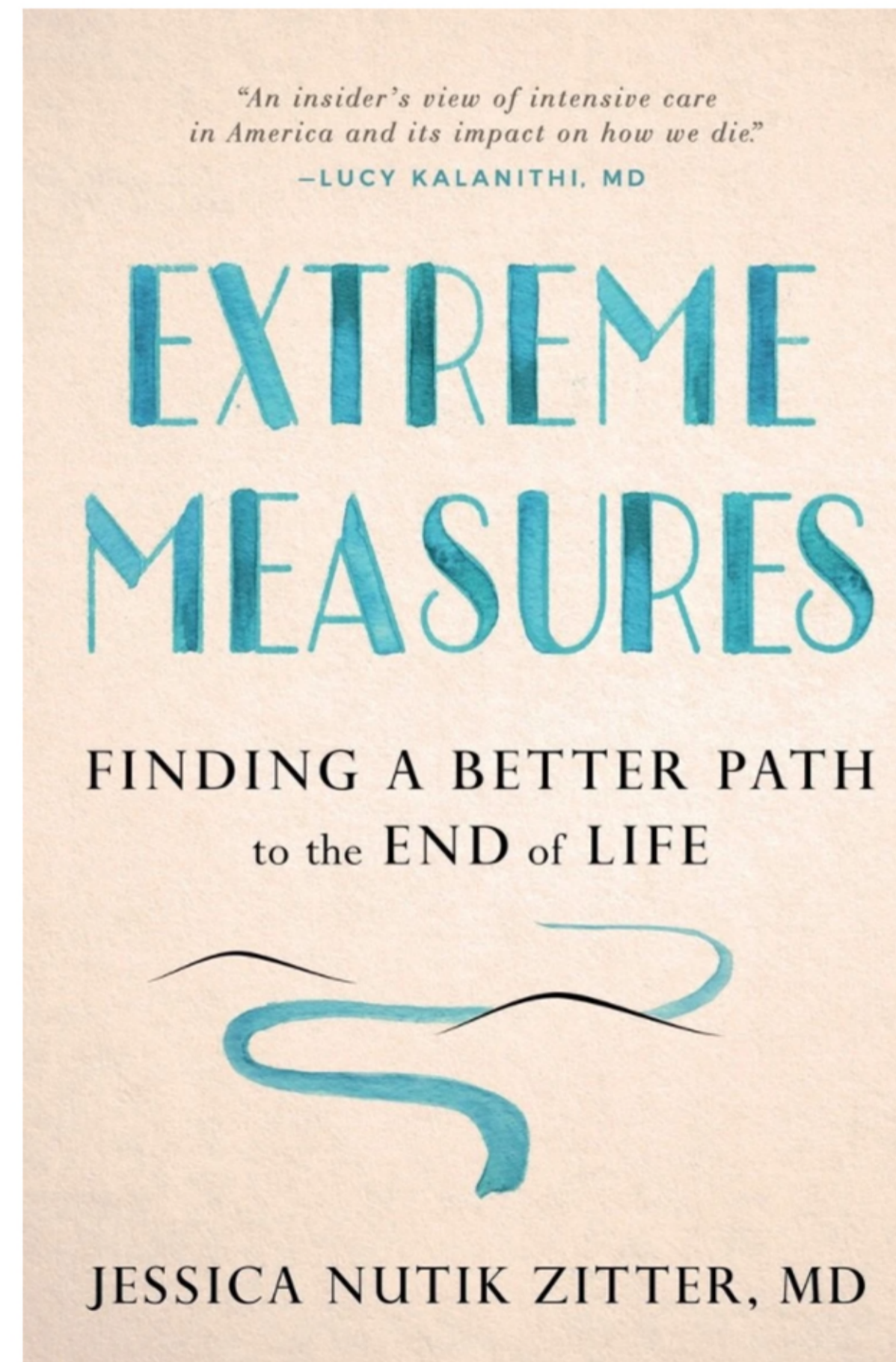
Figure 9: % of Patients by Race for 2018

Caucasian **82.0%**
African American **8.2%**
Hispanic **6.7%**
Asian/Pacific Islander **1.8%**
Other **0.5%**
Native American **0.4%**
Unknown **0.4%**

Source: CMS Data sourced by HCCI for NHPCO

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U.S. POPULATION BY RACE AND ETHNICITY in 2018

TOTAL: 60% | 18% | 13% | 6% | 2% | 1% | <0.5%

The nation's child population is more diverse than its total population.

CHILDREN: 50% | 25% | 14% | 5% | 4% | 1% | <0.5%

White | Hispanic or Latino | Black | Asian | Multiracial | American Indian or Native Alaskan | Native Hawaiian or Pacific Islander

The Culture of Medicine

LIVING WITH CANCER

At the End of Life, a Way to Go Gentle

"During the mid-20th century end-of-life (EOL) experiences were characterized by aggressive, costly interventions, but increasingly a turn towards palliative care and hospice has shifted away from such life-sustaining treatments. This turn has been perceived by many in bioethics, social sciences, and clinical medicine as improving medical treatment for the dying.

Overwhelmingly, contemporary studies of EOL health care identify greater intervention (such as ER visits, hospitalization, ICU admission, CPR, and/ or inpatient deaths) as evidence of inappropriate or lower quality EOL care.

Hauschildt K. Whose Good Death? Understanding Inequality and the End of Life. University of Michigan (PhD Diss.), 2019, p. 52

Table 1. Common Communication Pitfalls When Discussing Goals of Care for Patients with a Disability

| Unconscious bias	Supportive communication
Pity "This poor, unfortunate patient suffers from…" "I understand that you don't want to be dependent and a burden to your family."	**Respect** "Mr. Smith is a 56-year-old man who uses a wheelchair and volunteers as a patient advocate. He presents with…" "Adjusting to new functional limitations takes time. Maybe it would help if you hear directly from persons living with disabilities."
Abandonment "There is nothing we can do." "Call me if your pain is out of control."	**Maintaining and deepening connection** "Although the risks of this treatment outweigh the benefits in your case, I look forward to seeing you regularly and providing you with care. What are your hopes, needs, and fears?" "I'll call you to check on your pain. In the meantime, I'll consult with our palliative care team. There are support groups and mindfulness-based stress reduction classes that might interest you."
Misleading prognosis "You have less than six months to live."	**Sharing expertise and uncertainty** "Nobody knows for sure how long you have to live. It is especially difficult to make accurate estimates in persons with underlying disabilities. Most people with your condition live months rather than years."
Institutionalization "As your condition progresses, you may need to move to a nursing home."	**Home- and community-based services** "I'm going to refer you to our social worker, who can help you access extra help and home modifications so you can enjoy this time with friends and family."
Interventions without context "Would you want to live on a machine if you could never be taken off it?" "Would you want to be kept alive with a feeding tube?"	**Information about person-specific goals, risks, and benefits** "You have weak muscles that are affecting your swallowing and breathing. We can reduce the risk of aspiration pneumonia, improve your nutrition, and give you more energy with a tube for feeding and a home ventilator. It might help you to hear the stories of other people with neuromuscular disabilities who are living well on a home ventilator." Patients may appreciate help exploring stories online from other persons with neuromuscular disabilities. Examples of materials that show diverse representations of persons living with disabilities include http://dearjulianna.tumblr.com/ and https://www.youtube.com/watch?v=UfaGoTvWvMo.
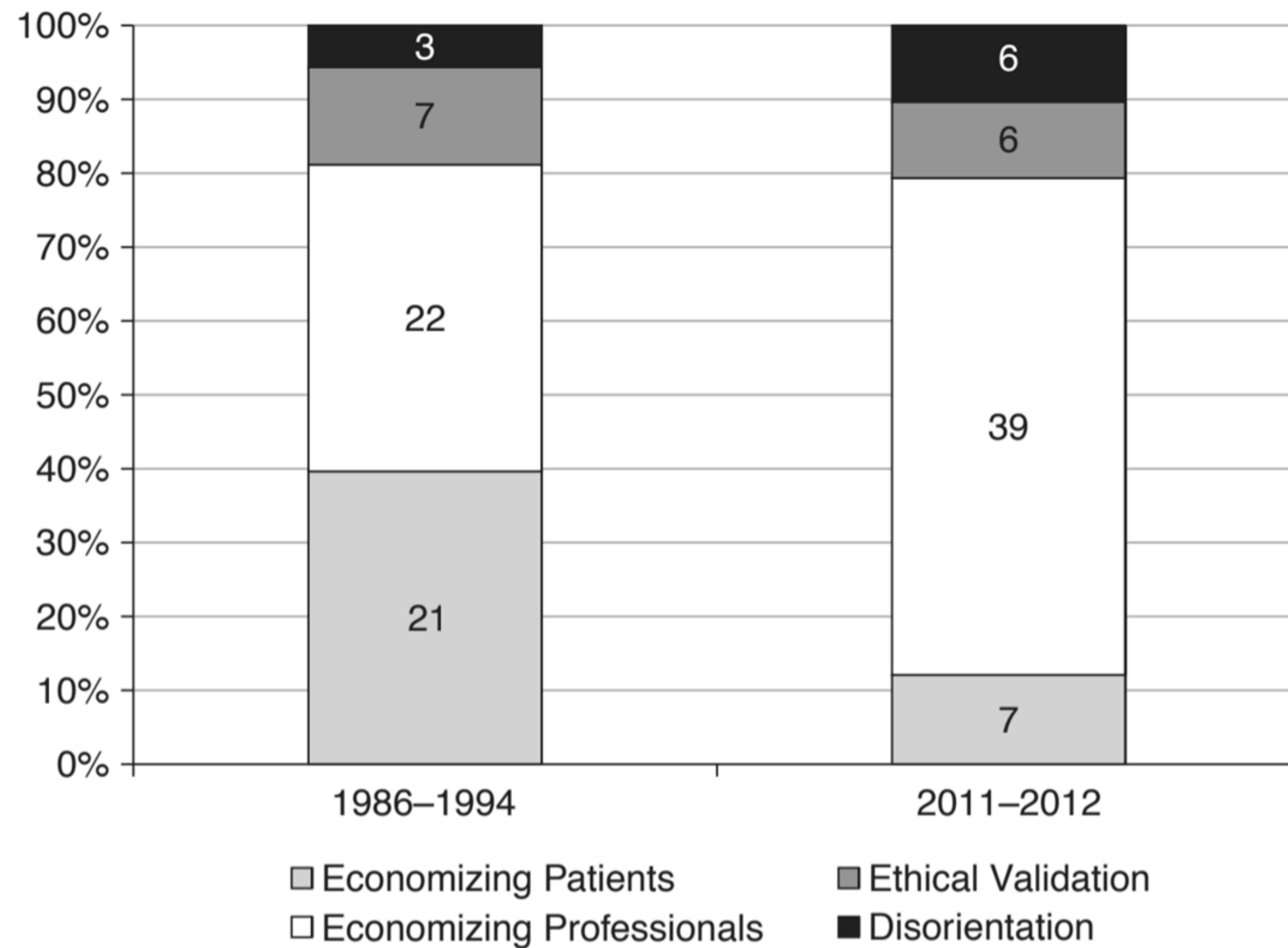
Figure 3.1. The historical change in bioethics consultations (end-of-life cases only).
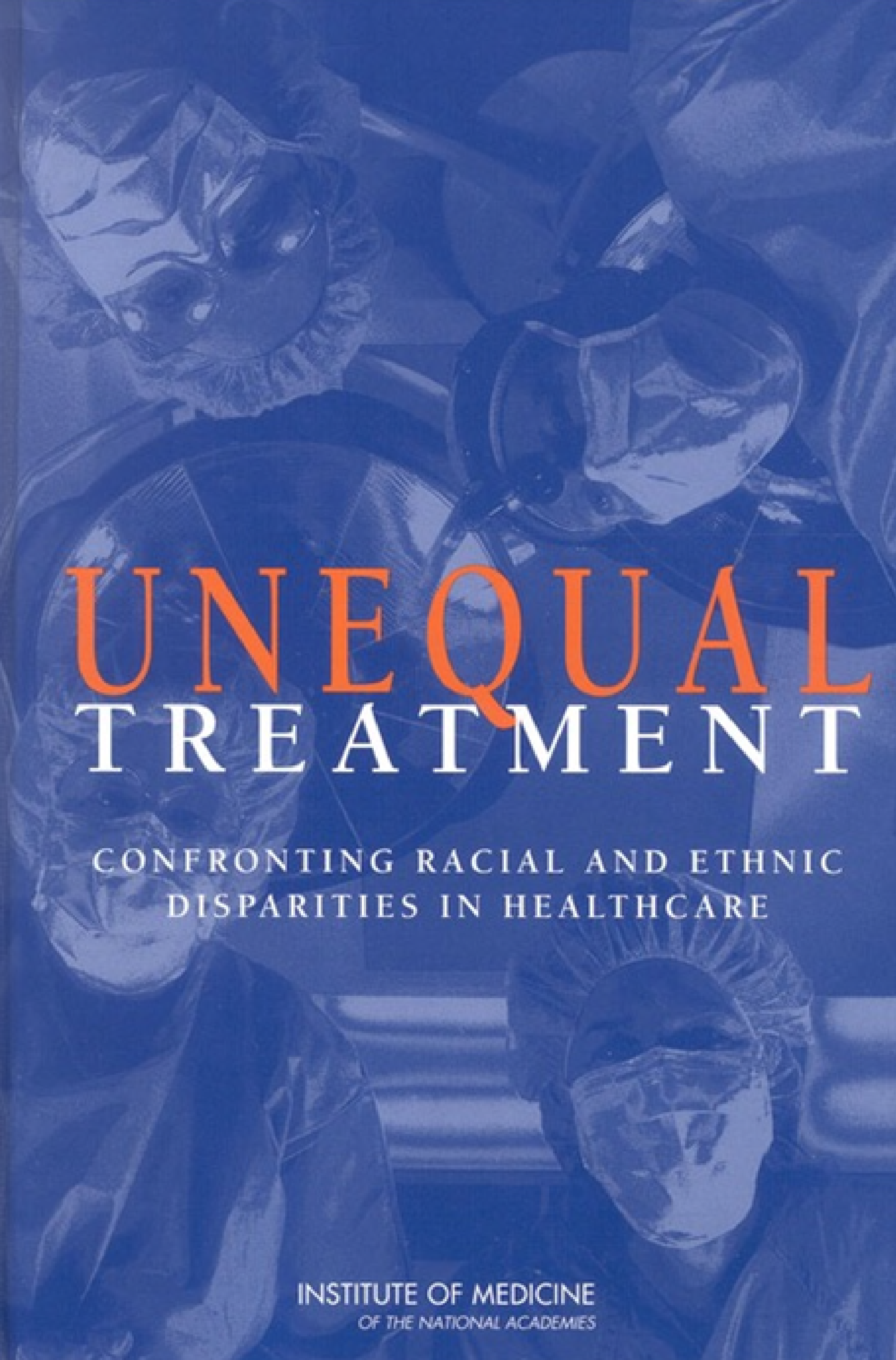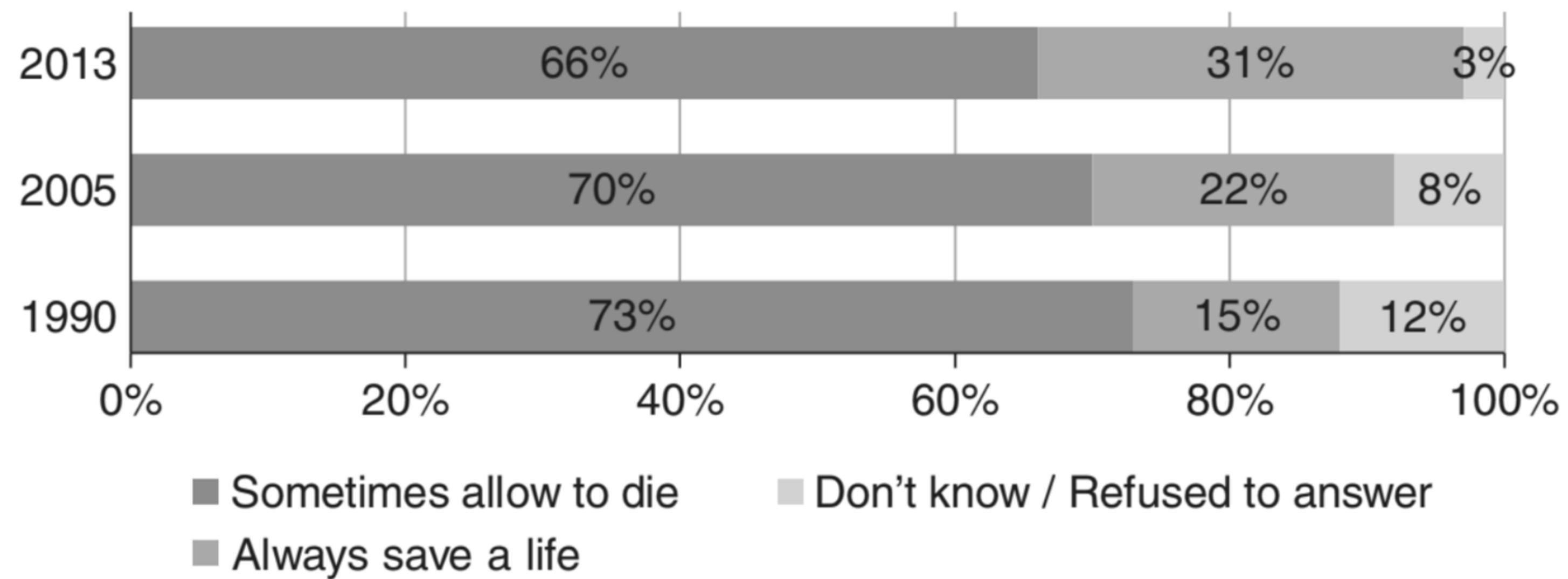
Figure 3.2. General positions on life prolongation. Data source: Pew Research Center, "Views on End-of-Life Medical Treatments," March 21–April 8, 2013.

Racial and Socioeconomic Inequalities in EOL Experiences

❖ *Intervention* perspective

❖ *Bias* perspective

❖ *Structural* perspective, including hospital-level factors

Adapated from Hauschildt K. Whose Good Death? Understanding Inequality and the End of Life. University of Michigan (PhD Diss.), 2019, p. 104f

Rationing

UNEQUAL TREATMENT

CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Patient characteristics (e.g., gender, age, race, and SES) have been shown to consistently predict diagnostic and treatment decisions, even when controlling for access to and utilization of medical care and when the presenting signs and symptoms of disease are held constant or controlled.

Race. Studies published after the 2003 IOM report *Unequal Treatment* suggest that profound discrepancies based on patient race and ethnicity persist across a diverse range of conditions, clinical scenarios, and stages of the life course.

Spencer KL, Grace M (2016) Social foundations of health care inequality and treatment bias. Annu Rev Sociol 42:101–120

LIFE AND DEATH IN A STORM-RAVAGED HOSPITAL

FIVE DAYS
AT
MEMORIAL

SHERI FINK

Winner of the Pulitzer Prize

TABLE 7] Multivariable Logistic Regressions for Odds of Choosing "Save the Most Life-Years" and "First Come, First Served" to Drive Decision-Making in Situations in Which Resources Are Limited

Characteristic	Often/Always Save the Most Life-Years Adjusted OR			Often/Always First Come, First Served Adjusted OR		
	OR	95% CI	P Value	OR	95% CI	P Value
Pilot vs nonpilot	0.24	0.16-0.38	< .001	0.60	0.34-1.05	.07
Age, y	...	...		1.01	0.99-1.02	.39
< 60	0.99	0.97-1.02	.644	...	...	
> 60	1.06	1.01-1.11	.03	...	...	
Baltimore vs non-Baltimore area	1.25	0.88-1.76	.21	0.78	0.43-1.42	.42
Female vs male	0.62	0.27-1.40	.25	1.26	0.68-2.32	.47
Race						
White	Reference	...	...	Reference	...	...
African American	0.34	0.21-0.58	< .001	2.36	1.29-4.29	.01
Other	0.84	0.46-1.52	.56	1.36	0.72-2.57	.34
Parent vs nonparent	0.85	0.46-1.60	.63	1.01	0.59-1.73	.98
Provider vs community	2.07	0.89-4.81	.09	0.57	0.19-1.78	.34

From "Mistrust" to Trustworthiness

IN THE WORK to resolve mistrust, the onus surely cannot lie with the potential trusters (patients) to reevaluate their understanding of the situation and place their trust in the American medical system.

George Floyd's Autopsy and the Structural Gaslighting of America

The weaponization of medical language emboldened white supremacy with the authority of the white coat. How will we stop it from happening again?

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By

Ann Crawford-Roberts, Sonya Shadravan, Jennifer Tsai, Nicolás E. Barceló, Allie Gips, Michael Mensah, Nichole Roxas, Alina Kung, Anna Darby, Naya Misa, Isabella Morton, Alice Shen

on June 6, 2020

A mural of George Floyd painted by the artists Donkeeboy and Donkeemom on the side of Scott Food Mart in Houston, Texas. Credit: Sergio Flores *Getty Images*

Editor's Note: The trial of Derek Chauvin, the former Minneapolis police officer charged in the death of George Floyd, began with the defense arguing that Floyd died of underlying medical conditions and drug use. This contradicts two autopsy reports—one by the Hennepin County Medical Examiner's Office and the other by private doctors commissioned by Floyd's family—that ruled the cause of death was homicide. This story from June 2020, written by 12 physicians, explains how inaccurately portraying the medical findings from Floyd's autopsy emboldens white supremacy under the cloak of authoritative scientific rhetoric. On April 20, 2021, Chauvin was convicted of second-degree murder, third-degree murder and second-degree manslaughter.

Next Directions

THANK YOU

Questions and Comments?