

Disparities in Serious Illness Care for African Americans

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OBJECTIVES

- Describe racial disparities in the quality of care for African Americans with serious illness.
- Describe how evidence-based palliative care interventions may address racial disparities.
- Describe opportunities to expand access to and acceptability of these interventions for racial and ethnic minorities.

A Personal Story



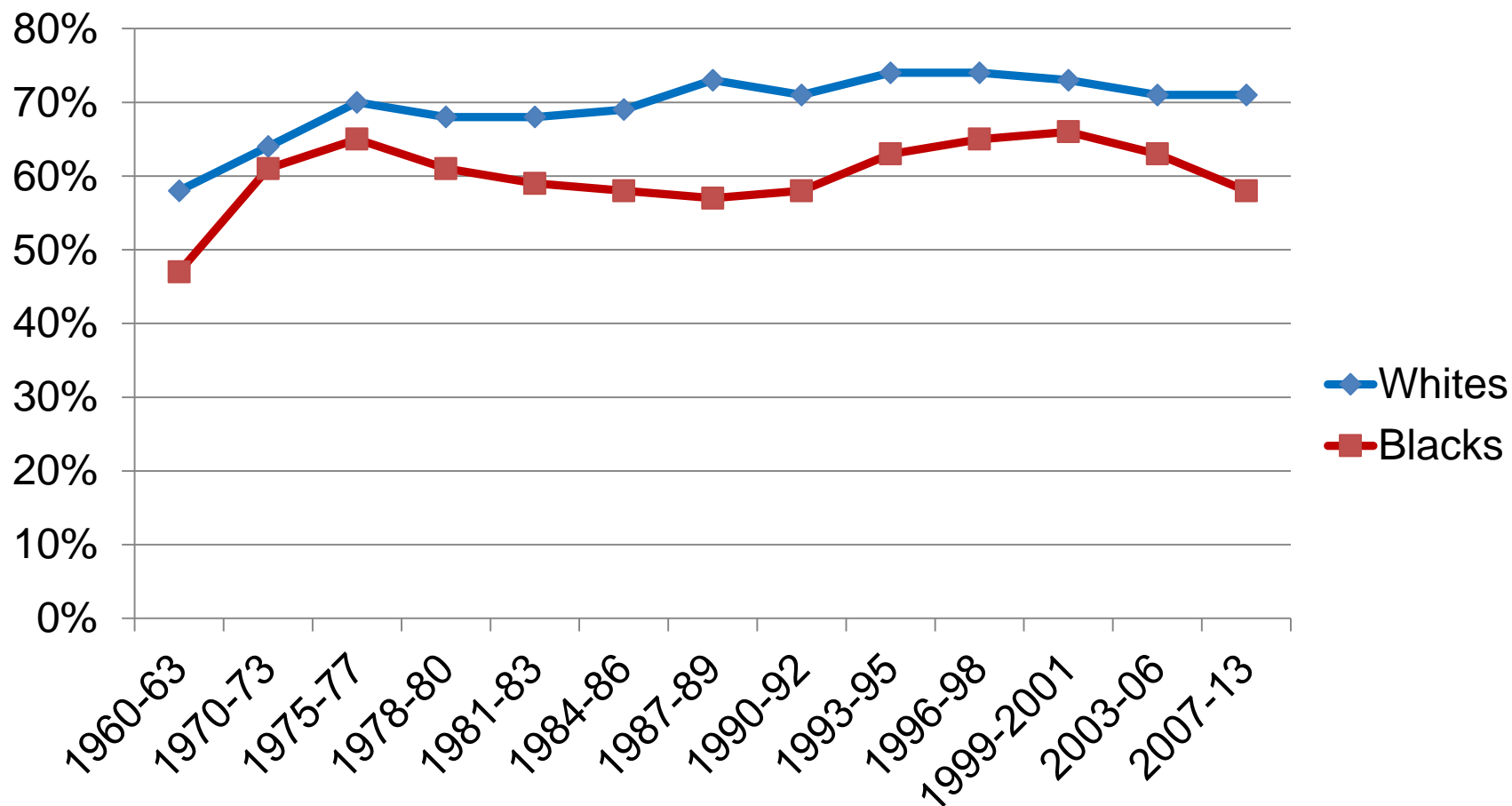
“With all of the medicines we have today, do you think she would have lived longer?”

“Even if she couldn’t be cured, do you think she would have lived better?”

**WOULD SHE HAVE LIVED
LONGER?**

She may have lived longer but...

5-Year Survival for Cervical/Uterine Cancer



**WOULD SHE HAVE LIVED
BETTER?**

The New York Times

Finding Good Pain Treatment Is Hard. If You're Not White, It's Even Harder.

By [ABBY GOODNOUGH](#)

AUG. 9, 2016



Disparities in Pain Management



Across settings, diagnoses, and age groups,
African Americans are **less likely** than Whites to
have pain adequately assessed and treated.

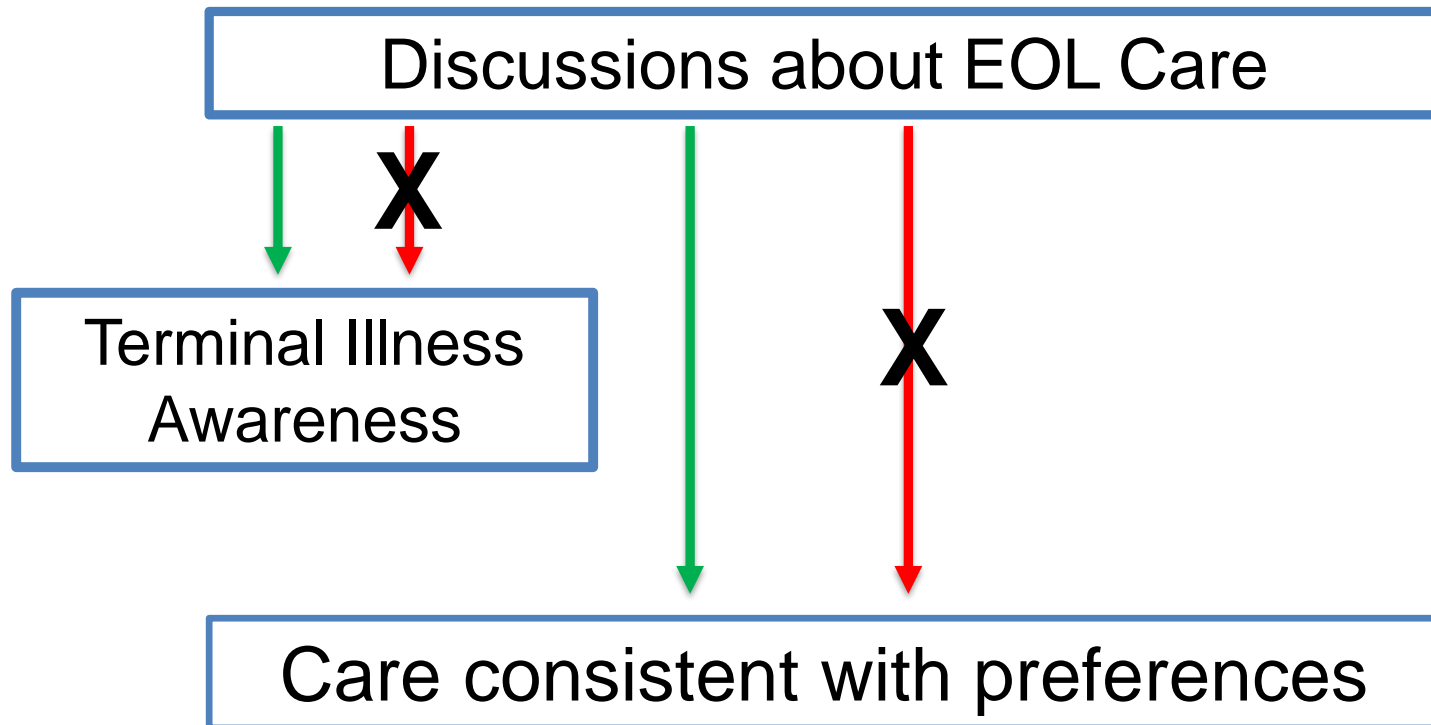
Disparities in Communication

- Communication less informative, partnering, and supportive
- Communication challenging in race-discordant interactions
- Absent or problematic communication
- Less Advance Care Planning



Periyakoil VS et al. PLoS One 2015;10(4):e0122321.
Cooper LA et al. Ann Intern Med 2003;139(11):907-15
Gordon HS et al. J Clin Oncol. 2006; 24(6):904-9
Welch et al. J Am Geriatr Soc 2005;53;1145-53

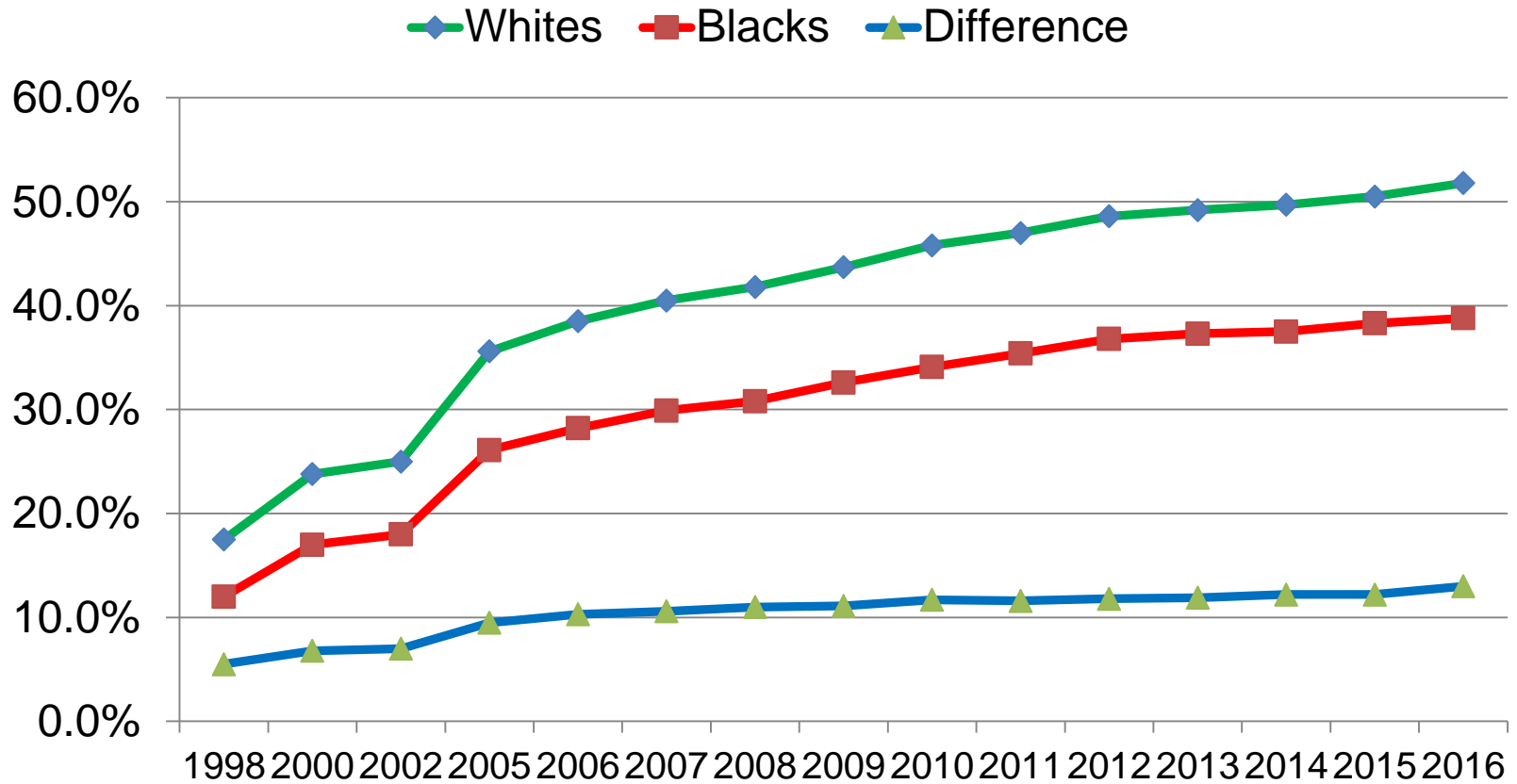
Disparities in Communication



 **Blacks**

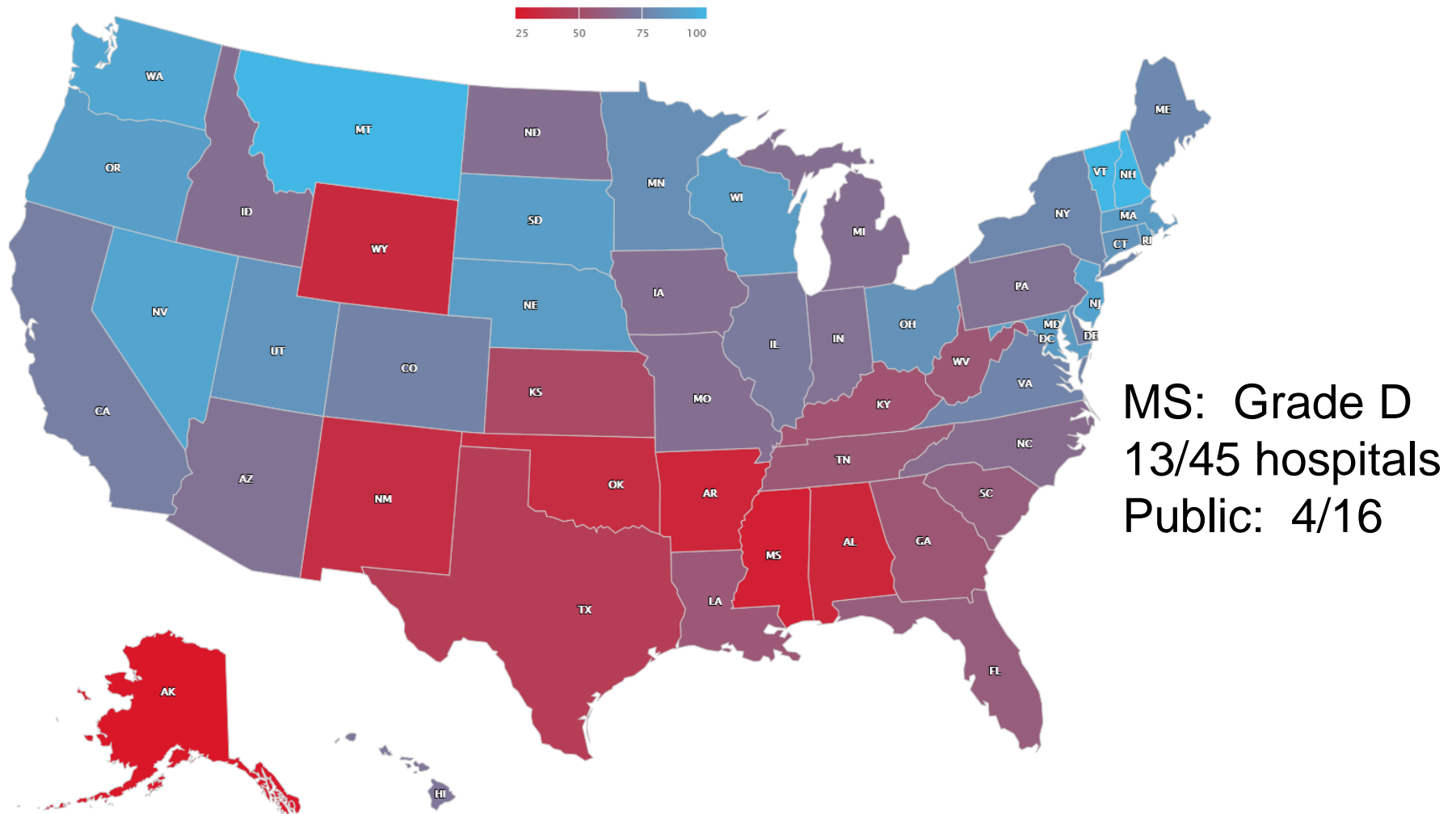
 **Whites**

Hospice Enrollment by Race



Medicare Payment Advisory Commission

Growth of Palliative Care in Hospitals



Highcharts.com © Natural Earth

<https://reportcard.capc.org/>

Responding to Aunt Janie



“With all of the medicines we have today, do you think she would have lived longer?”

“Even if she couldn’t be cured, do you think she would have lived better?”



**Follow the evidence
wherever it leads, and
question everything.**

Neil deGrasse Tyson

“ quote fancy

PALLIATIVE CARE

Palliative Care Reduces Disparities

- Hospice referral
- Symptom burden
- Discussion of Tx preferences
- Completion of Advance Directives
- Use of Pain Medications



Sharma et al. J Clin Oncology 2015;31:3802-08

Smith et al. J Pain Symptom Manage 2015;49:369-70

ADVANCE CARE PLANNING

ACP Interventions May Reduce Disparities

- Advance directive completion
- Care consistent with preferences
- Satisfaction with communication and quality of care



Disparate outcomes for African Americans vs Whites

HOSPICE USE

Hospice Use Reduces Some Disparities

- Satisfaction with quality of care
- Communication
- Emotional and Spiritual Support



Rhodes RL et al. J Pain Symptom Manage 2007;34:472-479

What are the barriers?

→ Patient Factors

- Knowledge
- Preferences
- Spiritual Beliefs
- Trust in Healthcare System

→ Provider Factors

- Communication
- Bias

→ Organizational and System Factors

- Payment Structures
- Insurance and Income
- Geography

Johnson et al. *J Palliat Med* 2013;16:1329-34

Goepp et al. *Am J Hosp Palliat Care* 2008 25:309

Hoffman, KM. *Proc Natl Acad Sci* 2016;113(16):4296-301

OPPORTUNITIES TO IMPROVE CARE EXPERIENCE

Community Education, Outreach and Partnership

→ Improves Knowledge, Trust, Whole-person care

“I think it [church-based education] would have influenced my decision more because of them coming out and going through something I believe in, which is the spirituality piece. I would have received more information about it before getting to the point we’re in now.”



Work Force Diversity and Training

- Increase diversity among healthcare providers—trust, interpersonal care, access
- “We had a black chaplain and a black nurse. I was very pleased. Lots of times, African Americans experience things in life different than other groups and that allows individuals to be able to relate a little better.”



Work Force Diversity and Training

→ Cultural Competence Training—provider knowledge and skills; patient satisfaction



Work Force Diversity and Training

→ Inclusion of community health workers and others

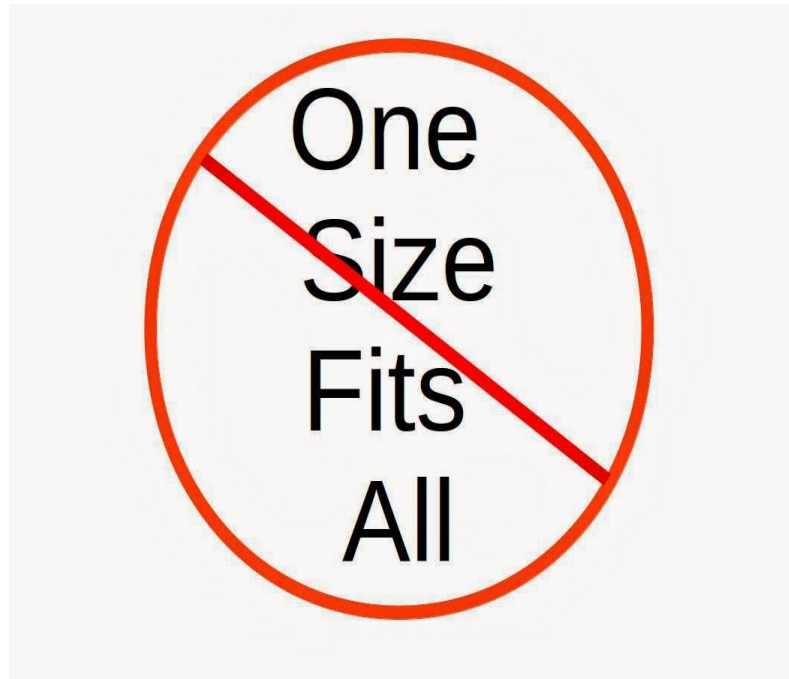
“African Americans need information from a trustworthy source. This involves learning from peers, someone “like me.”

**African American
community member**



One Size Does Not Fit All

- Programs, policies, and systems which accommodate a range of beliefs, values, concerns, and approaches



Equitable Care in Serious Illness: The Fierce Urgency of Now



April 1967

“We are now faced with the fact that tomorrow is today. We are confronted with the fierce urgency of now. This is no time for apathy or complacency. This is a time for vigorous and positive action.”