

# What is Palliative Care Anyway?

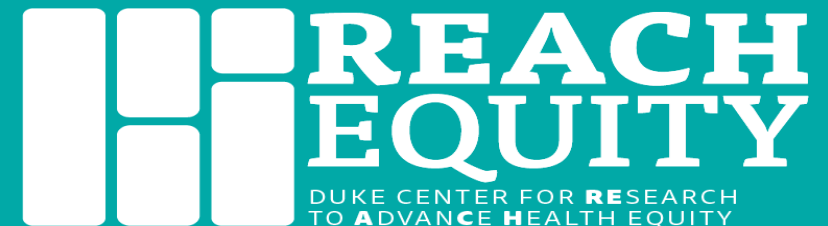
## Tailoring Messages to Reach Specific Audiences

**Kimberly S. Johnson MD MHS**

Professor of Medicine

Division of Geriatrics

Director, Duke Center for Research to Advance Healthcare Equity

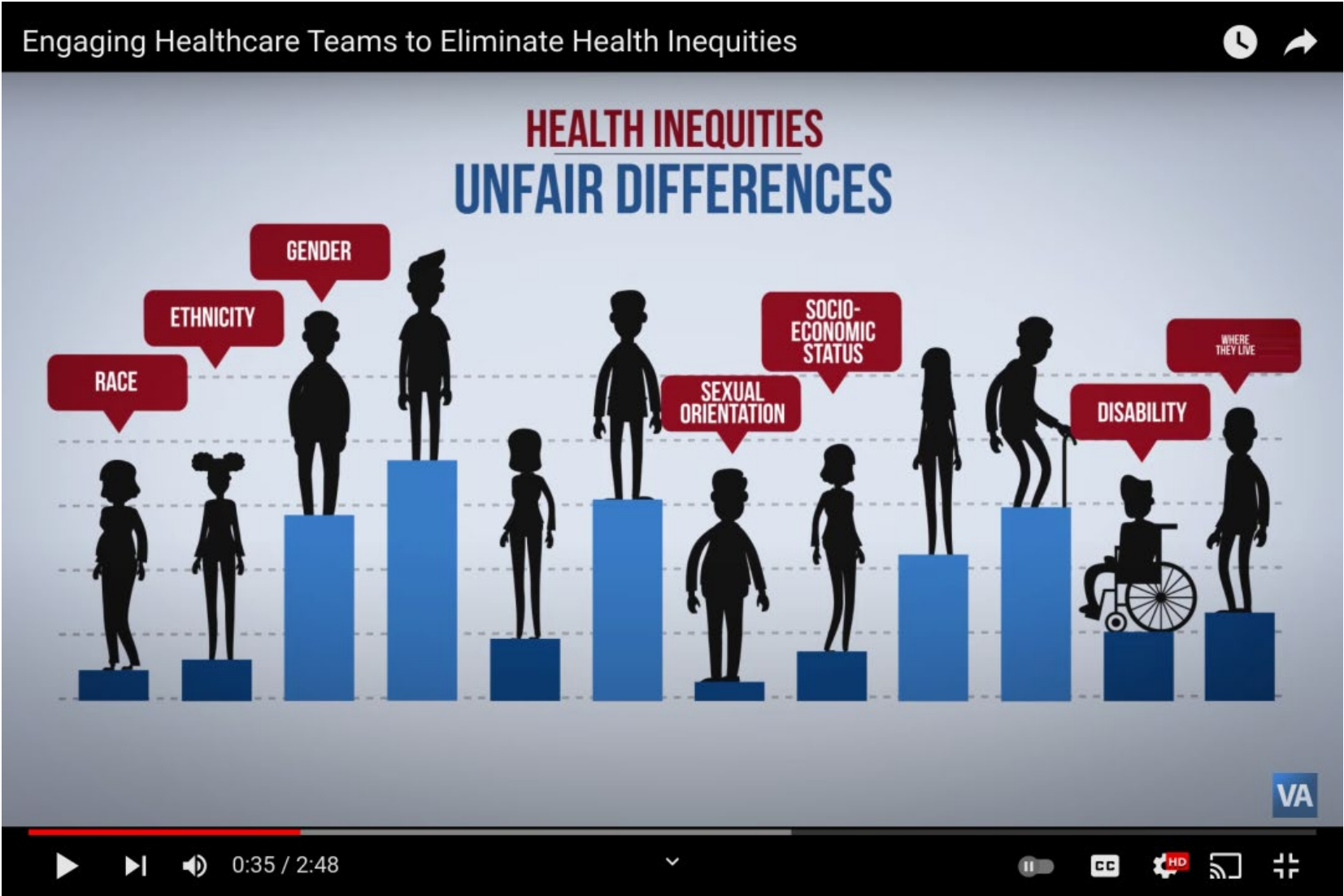


“What exactly do you do?”

“That’s nice, but with all of the problems that Black people have, shouldn’t you spend your time curing cancer or something?”



# Context Matters



# Health Disparities are Widespread

**20%** less likely to receive tx for **depression**

**2X** more likely to die from **asthma**

**3X** more likely to develop **ESRD**

**2X** more likely to die from **prostate cancer**

**2X** more likely to die from **cervical cancer**

**9X** more likely to be diagnosed with **HIV** and **8X** more likely to die



**40%** more likely to die from **stroke**

**30%** more likely to die of **CVD**

**40%** more likely to die from **breast cancer**

**40%** more likely to be **obese**

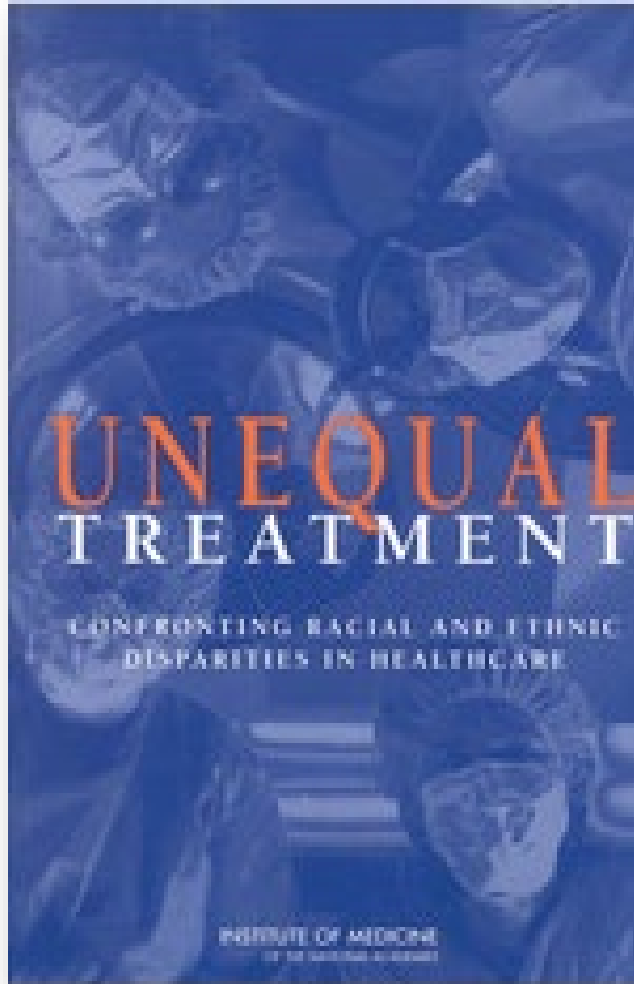
**2.5X** more likely to die during **pregnancy**

**60%** more likely to have **diabetes**

**2X** more likely to die as an **infant**

[www.familiesusa.org/health-disparities](http://www.familiesusa.org/health-disparities)

# Healthcare Disparities are Widespread



- Less Access to Healthcare
- Even with access, lower quality care
  - Across settings, diagnoses
    - Cardiac procedures
    - Cancer treatments
    - Pain medications
    - HIV medications
    - Kidney transplantation
    - Diabetes care

# DIFFERENTIAL HEALTHCARE EXPERIENCES

“If you aren’t of the right group, you get lousy treatment” (participant 5)

*JAMA Netw Open.* 2023;6(7):e2321746.  
doi:10.1001/jamanetworkopen.2023.21746

HISTORY & CULTURE | RACE IN AMERICA

## Black Americans see a health-care system infected by racism, new poll shows

## New poll shows Black Americans put far less trust in doctors and hospitals than white people

*Many report health care providers didn’t believe them and denied tests and treatment*

BY JESSE WASHINGTON



# Context Matters



<https://www.nytimes.com/2021/08/17/health/racial-disparities-health-care.html>

# Disparities in Serious Illness Care: Context Matters

- ✓ Pain Management
- ✓ Communication
- ✓ Shared Decision Making
- ✓ Care Consistent with Preferences
- ✓ Palliative Care Services



# Messaging: What do you know?

## WHAT WE LEARNED

---

26%

of congregants are not at all or only a little informed about hospice care.

45%

of congregants are not at all or only a little informed about palliative care.

34%

of congregants were not at all or only a little informed about advance care planning (ACP).

# Beliefs about Palliative Care

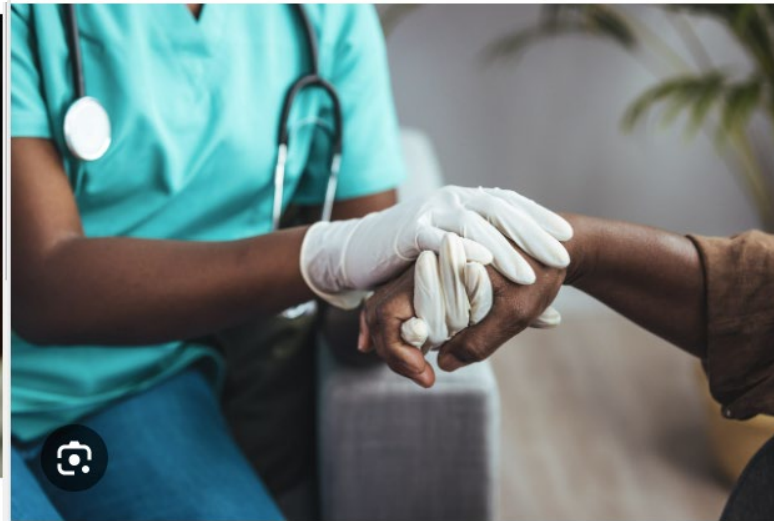
- ✓ No experience with palliative care
- ✓ Palliative care means giving up
- ✓ Palliative care makes me think about death
- ✓ Palliative care may be against my religious beliefs

# Messages



Family, fear, and faith: Helping Black patients with end-of-life...

[Visit >](#)



Addressing Disparities in Hospice and Palliative Care Access for Blac...

[Visit >](#)

Images may be subject to copyright. [Learn More](#)



Hope and peace of mind reign at today's African American funeral...

[Visit >](#)

# Tailoring Messages: Highlighting Benefits that Matter

- **Addressing variation in treatment preferences**
  - You do not have to give up anything
  - You may continue to receive curative or disease-directed therapies while you receive palliative care. Both... AND NOT Either.... OR
  - You may continue to see your doctors and return to the hospital.

# Tailoring Messages: Highlighting Benefits that Matter

- **Addressing concerns about a focus on death**
  - I am not talking about hospice.
  - You may receive palliative care at anytime beginning with diagnosis of a serious illness.
  - The focus of palliative care is not about preparing for death or end-of-life care.
  - The goal is to improve your quality of life. “It’s about living your best life.”

# Tailoring Messages: Highlighting Benefits that Matter

- **Exactly what do you do and how can you help?**
  - People with serious illness have uncomfortable symptoms like pain, nausea, and shortness of breath. Palliative care can help.
  - You and your family may have to make important decisions about your medical care. We try to understand what is important to you... what your goals are.. And which treatments may help you to achieve those goals.
    - Emphasize that palliative care is about honoring patient and family choices
    - We have no agenda.
  - We want to help make sure that you receive the best care possible
    - Important when many will have experiences where this was not true.

# Storytelling: Words and Images Matter

- Papa: Black man with dementia and behavioral disturbances who lives alone with his wife who is concerned that she will have to put him in a nursing home.
- James: Black man with prostate cancer metastatic to the bone with poorly controlled pain and significant immobility due to pain.

# Messengers Matter

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

**African American  
community member**

A lot of people don't know what palliative care is and may be afraid to talk about it. A church-based program can bring education that is needed in a safe space that people trust. Keep it simple, short, and sweet.

**African American  
community member**

Shared personal and cultural values and experiences

Trusted Community Organizations (civic groups, fraternities, sororities)

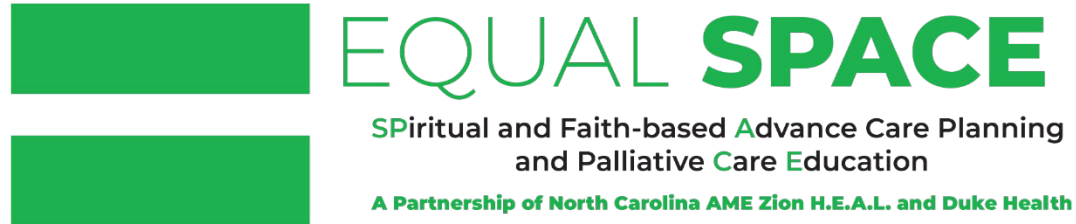
Community Influencers

Community Health Workers

# EQUAL SPACE

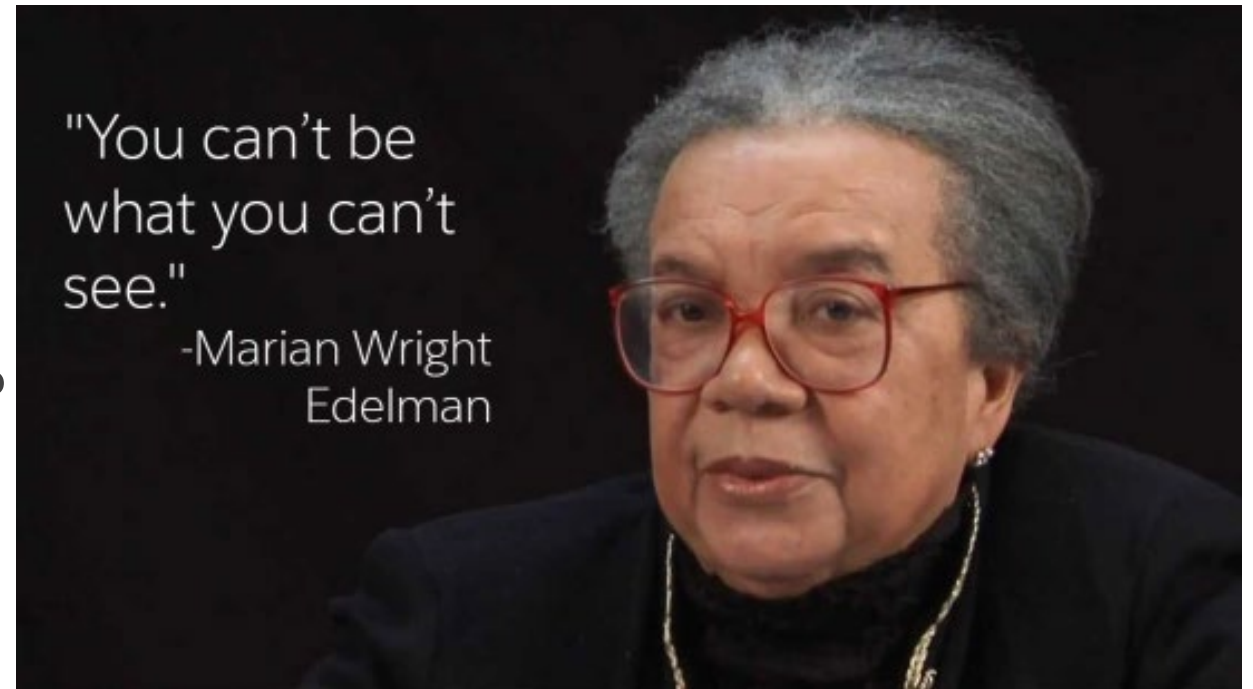
- Develop and implement a culturally tailored, faith-based palliative care education and ACP curriculum informed by congregants.

Train 52 Clergy & Health Ministry leaders



# Mode and content Matter

- Where do the people you want to reach receive healthcare messages?
  - Social Media
  - Online (which sites)
  - Radio
- Attention to health literacy
- Attention to images
  - Are these services for people like me?



# Context Matters: Understanding Experiences and Goals

“People are not just a collection of molecules and tissues and organs. We have to understand what the person with the disease or illness wants to accomplish.”

