

# NHPCO Project ECHO 2023

## *Equity Where It Matters*

Topic: Supporting African American Patients at the End-of-Life

Presented by: Altonia Garrett, MBA, MHA, RN  
Dr. Elisha Hall, PhD

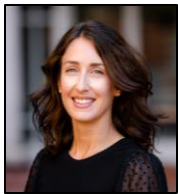
Date: February 2, 2023

# NHPCO Project ECHO Team



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# Disclosures

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## Disclosure

The planners and faculty disclose that they have no financial relationships with any commercial interest.

## Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

## Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

# Ground Rules and Video Teleconferencing Etiquette

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- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

# Today's Agenda

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- Introduction of Faculty – NHPCO Team
- Didactic Presentation: Supporting African American Patients at the End of Life – Faculty
- Case Study Presentation: Fighting to the End: African Americans and End-of-Life Care Decisions – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

# Session Faculty

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Altonia Garrett, MBA, MHA, RN

Executive Director, AccentCare, Washington, DC  
Founding Executive Director, Capital Caring's Center for Equity, Inclusion and Diversity  
Senior Advisor, Innovation and Health Equity- National Partnership for Healthcare and Hospice Innovation (NPHI)  
Member, ACHE



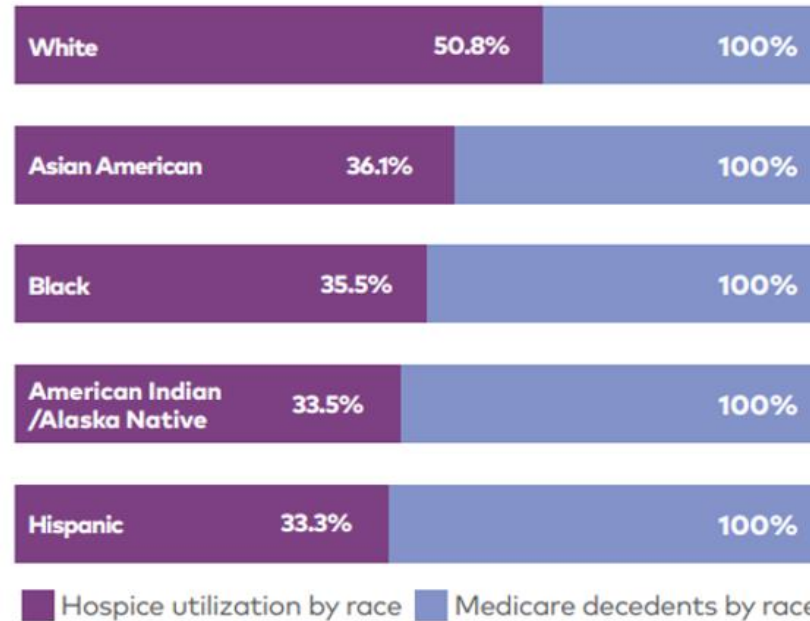
Dr. Elisha Hall, PhD

African American Engagement Director, Compassion & Choices, IL  
Founder, African American and Indigenous Knowledge Institute (AIKI)

# Didactic Presentation

# Hospice Utilization

**Figure 9: Share of Medicare decedents who used hospice, by race**



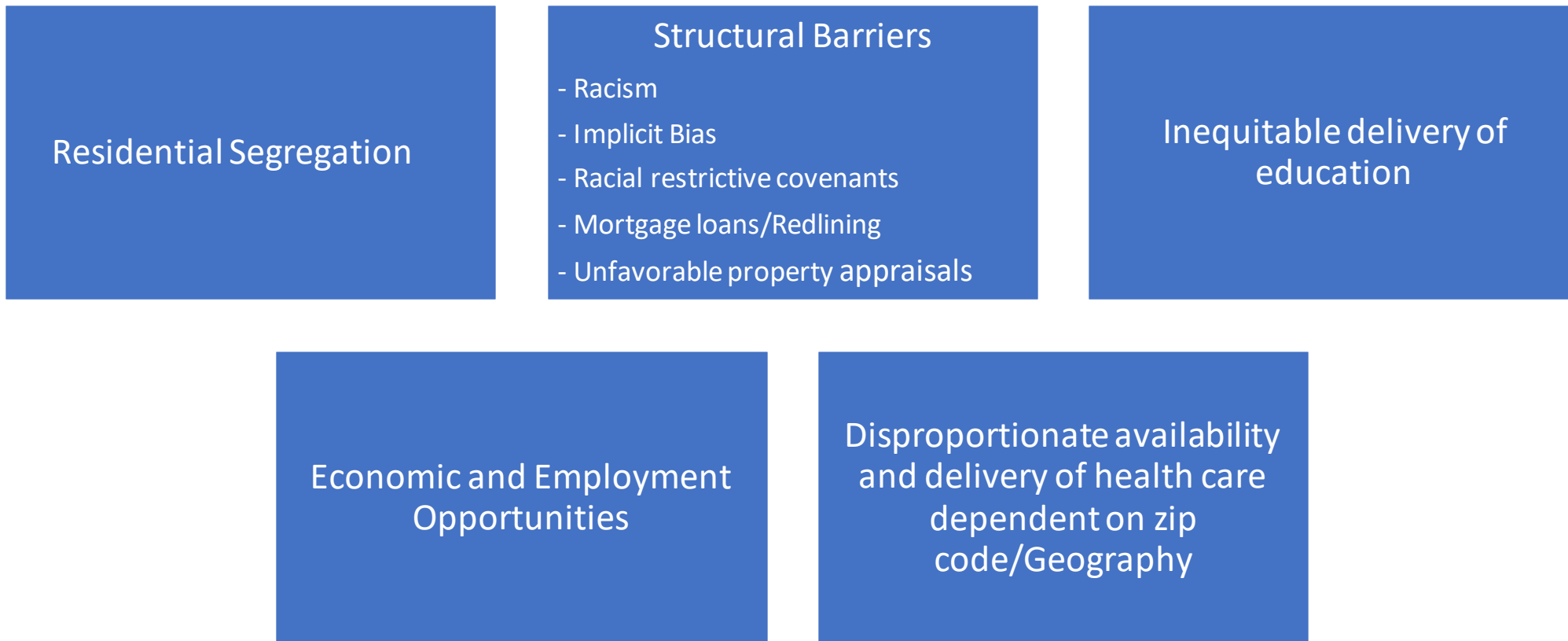
Source: MedPAC March 2022 Report to Congress, Table 11-3

2022 Edition: Hospice Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization.



# Barriers to Care: Root Causes

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Source: Dawes, Daniel E. (2020) The political determinants of health

# Barriers to Care

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Feeling of an abandonment of caregiving/care taking responsibilities/family resistance

- Ethos of “we take care of our own”

Misconceptions and thoughts of hastening death

Lack of awareness

- Location
- Costs

Mistrust of the healthcare system and government funded programs

- Tuskegee Study from 1932 to 1972
- Gynecological experimentation 1845-1849
- Improper pain assessment and management

Spiritual and Religious practices and beliefs

Sources:

2023, African-American Outreach Guide. Alexandria, VA: National Hospice and Palliative Care Organization.

Rhodes RL, Batchelor K, Lee SC, Halm EA. Barriers to end-of-life care for African Americans from the providers' perspective: opportunity for intervention development. Am J Hosp Palliat Care. 2015;32(2):1

Washington, Harriet A. "Medical apartheid : the dark history of medical experimentation on Black Americans from Colonial times to the present." New York: Doubleday, 2006.37-143

# The role of faith and religion

Faith plays a major role in the Black/African American community – 47% of the Black/African American community attend church at least once per week.

For many,

- Religion and church is fundamental to all being, knowledge, life's vision
- God is in charge
- Pastor's role is key
- Hope for a miracle in serious illness always exists

There is a key focus on life and living – a celebration of life and maintaining hope

**59%** vs 50%

NHPCO's study, "Hospice through the DEI lens", showed that black respondents are significantly more likely to want religious or spiritual component to hospice compared to White respondents.

Sources :

2023, Hospice Through the DEI Lens. Alexandria, VA: National Hospice and Palliative Care Organization.

Johnson KS, Elbert-Avila KI, Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. Journal of the American Geriatrics Society. 2005;53(4):711-719

<https://www.pewresearch.org/religion/religious-landscape-study/compare/attendance-at-religious-services/by/racial-and-ethnic-composition/>

# Definitions for Advance Care Planning

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Advance directive is a general term for any document that contains instructions pertaining to a person's wishes related to medical treatment if they can not make care decisions on their own. Everyone over 18 should have an advance directive to increase the likelihood you will get the care you want. **Common advance directives include:**

- **Living will (“what I want”)**
- **Medical durable power of attorney (“who will speak for me”) - this person is sometimes referred to as a health care proxy**
- **Do not resuscitate and do not intubate orders; simple orders indicating when or if you want this care**
- **POLST: Portable Medical Order (described below)**

In most states, a lawyer is not required to fill out an advance directive; one simply needs to sign in front of the required witnesses. Advance directives are one important output of advance care planning; however, they are not the only aspect. Understanding and communicating your priorities is just as important.

# Considerations for Advance Care Planning

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## Benefits of ongoing advance healthcare planning conversations:

- A better chance that your loved ones and health care providers will honor your health care wishes
- Less confusion and family conflict
- A 'gift of love' for those who will need to make decisions
- Modeling for children and parents and friends
- Advance directives combine both pieces, the what and the who
- Documents and regulations change from state to state
- Some states have multiple documents, others just have one
- Compassion & Choices End of Life Information Center links to the state pages for the state approved forms
- People can use forms other than the state forms, but the state forms will include instructions about state specific regulations so they are recommended

# Considerations for Advance Care Planning

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African Americans are less likely to complete advance directives and are; more likely to prefer more aggressive treatments like:

- Mechanical ventilation
- Feeding tubes

Goals of Patient Treatment are:

- Less often discussed by doctors
- Less often recorded by doctors in the chart
- Even when African Americans have written goals of care in chart, often not followed or respected.

African Americans more times than not have a lack of knowledge of prognosis

Sources: Wicher CP, Meeker MA. What influences African American end-of-life preferences? Journal of health care for the poor and underserved. 2012;23(1):28-58.

# Overcoming Barriers

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- Cultural Sensitivity training for providers
- Creative use of mixed media to educate and patients and families
- Communication strategies
  - Speak to people not at them
- Teams reflective of the community being served
  - Partner with trusted community partners – including the faith community
- Understand and acknowledge the role that faith plays in healthcare decision making
  - Reframe things – lean into faith
- Help families understand that support of hospice is additional support (caregiver tool) – strengthening what they do not abandoning it

Source:

2023, Hospice Through the DEI Lens. Alexandria, VA: National Hospice and Palliative Care Organization.

Rhodes, R. L., Batchelor, K., Lee, S. C., & Halm, E. A. (2015). Barriers to end-of-life care for African Americans from the providers' perspective: opportunity for intervention development. *The American journal of hospice & palliative care*, 32(2), 137–143. <https://doi.org/10.1177/1049909113507127>

# Case Study Presentation

## Fighting to the End: African Americans and End of Life Care Decisions



# Situation

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A woman was diagnosed with advanced stage IV adenocarcinoma of the lung (lung cancer), only after having symptoms of a moist cough that would not go away. It was noted that she had never really been sick her entire life, nor had she ever smoked. However, her husband had smoked, and she spent years breathing in secondhand smoke.

Source: Townsend, Apollo. (2016). Fighting to the end: African Americans and end of life care decisions. *Nursing and Palliative Care*. 1. 59-61. 10.15761/NPC.1000116.

# Background

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- A prominent, well-respected member of a large African American church. She is God fearing, and a strong woman of faith with a spirit of generosity. She is known for her listening ear and sound biblical advice. She was dependable and always there to visit sick and shut in – often cooking meals to help ease families stress of caregiving. She even taught Sunday school and was viewed as the epitome of a godly woman.
- Upon learning the diagnosis, her response was “God’s got this”, and her assurance of God’s never-failing love and healing power remained at the forefront of every conversation and every health care decision over the next several months.
- Agreed to chemotherapy as a treatment option, with committing to only three treatments: “one for the Father, one for the Son, and one for the Holy Spirit”.
- Viewed physicians as helpers in the healing process but only God could guarantee life.

Source: Townsend, Apollo. (2016). Fighting to the end: African Americans and end of life care decisions. *Nursing and Palliative Care*. 1. 59-61. 10.15761/NPC.1000116.

# Assessment

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- The patient connected with a well-respected oncologist and at her first appointment, she was told that if she followed the treatment plan, her life could be extended 2 more years.
- After two chemotherapy treatments, the tumor mass appeared to be shrinking and the patient and the oncologist were hopeful, and a third treatment was completed.
- After the third treatment, significant side effects arose: mouth sores, rashes, extreme fatigue, and abnormal blood counts. With the unbearable side effects and her only planning to do three treatments, she was now adamant to stop chemotherapy.
- In the conversation with the oncologist about stopping chemotherapy treatment, the oncologist revealed he had given higher than normal doses than originally agreed upon in her third dose.
- The patient expressed her disappointment and shared she would be moving her care to her primary care physician (PCP).

Source: Townsend, Apollo. (2016). Fighting to the end: African Americans and end of life care decisions. Nursing and Palliative Care. 1. 59-61. 10.15761/NPC.1000116

# Outcomes

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- The PCP worked with her to palliate her symptoms over several months and then ultimately referred her to hospice care.
- Her PCP was aware of her spiritual beliefs and incorporated that into his approach with her, even saying he would be praying for her.
- She never hesitated to call her PCP with symptoms or concerns.
- When agreeing to hospice care, she explained to the family she had not given up, but she needed support from professionals trained in palliative care and she would continue to fight and believe in God for healing.
- By the time she was admitted to hospice, she went directly to a hospice inpatient unit, where she spent her final days where she was visited by church friends sharing church news – she would smile
- She died comfortable on Easter Sunday morning.

Source: Townsend, Apollo. (2016). Fighting to the end: African Americans and end of life care decisions. Nursing and Palliative Care. 1. 59-61. 10.15761/NPC.1000116

# Discussion and Recommendations

# Discussion

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- What could the oncologist have done differently?
- Did the oncologist breach trust regarding the treatment plan or was it just poor communication?
- What behaviors from the PCP should be always practiced?
- What lessons are practices can hospice and palliative care providers take away from this case?
- Are there any other points that stand out?

# Recommendations

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- In this case, the oncologist should have established a stronger physician – patient relationship; asking questions about cultural and religious beliefs – and acknowledge them.
  - Understanding these beliefs helps have a better understanding how they may impact care planning choices.
- With the mistrust of the health care system being identified as a significant barrier to hospice care/access, the oncologist should not have increased the medications with out a discussion with her. This is/or can be seen as dishonest AND poor communication.
  - All patients should have open, honest, and well-informed understanding and consent to treatment options.
- The PCP was at an advantage as he has known the patient for years and was aware of and acknowledged her strong faith foundation, even offering to pray for her.
- The patient trusted her PCP and accepted his recommendation for hospice readily and even worked together on how to share the update with the family.
- Hospice and Palliative Care providers can meet patients where they are and offer open access or expanded care options
- For many in the Black/African American community – end of life care decisions may represent more of a spiritual choice not a medical choice.

Source: Townsend, Apollo. (2016). Fighting to the end: African Americans and end of life care decisions. Nursing and Palliative Care. 1. 59-61. 10.15761/NPC.1000116

# Key Takeaways

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## **Disparity in Hospice Utilization:**

- A racial disparity in hospice utilization and Medicare decedents who use hospice exists, and this is influenced by the social determinants of health (SDOH).
- Barriers to considering hospice may include family reluctance to release their own care, misconceptions around hastening death, mistrust of the healthcare system due to past experimentation, and spiritual and religious beliefs.

## **The Role of Faith:**

- In the Black/African American population, faith often plays a major role in decision making and there may be a strong presence of faith beliefs in the illness experience where God is recognized as in charge and the Pastor's role is fundamental.
- Hope for a miracle is a common sentiment.



# Key Takeaways

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## **Advance Directives:**

- For some African American communities, completing advance directives is less likely to occur and choosing the aggressive treatment prevails.
- In addition, health providers are less likely to discuss goals of patient treatment, and even if those conversations do occur, African American patients' goals are less likely to be respected nor followed. Coupled with a lack of knowledge of prognosis and the timing of disease, advance directives for African American patients can be difficult to attain.

# References

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- 2022 Edition: Hospice Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization.
- 2023, African-American Outreach Guide. Alexandria, VA: National Hospice and Palliative Care Organization.
- 2023, Hospice Through the DEI Lens: A research study identifying barriers to hospice care in underserved communities. Alexandria, VA: National Hospice and Palliative Care Organization
- Hostetter, Martha and Klein, Sarah. "Understanding and Ameliorating Medical Mistrust Among Black Americans," Transforming Care (newsletter), Commonwealth Fund, Jan. 14, 2021. <https://doi.org/10.26099/9grt-2b21>
- Rhodes, R. L., Batchelor, K., Lee, S. C., & Halm, E. A. (2015). Barriers to end-of-life care for African Americans from the providers' perspective: opportunity for intervention development. *The American journal of hospice & palliative care*, 32(2), 137–143. <https://doi.org/10.1177/1049909113507127>
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# Session Evaluation and Certificate of Completion

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- Your feedback is valuable as we plan upcoming sessions!
  - Please complete the [Project ECHO Session Evaluation](#)
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
  - *Project ECHO Session Evaluation*
  - *Project ECHO Post-Session Knowledge Check*

# NHPCO Health Equity Certificate in Hospice and Palliative Care

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- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
  - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 18 sessions in the *Equity Where It Matters* series
- To receive participate in the Health Equity Certificate, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
  - *Project ECHO Session Evaluation*
  - *Project ECHO Post-Session Knowledge Check*

# Upcoming Sessions

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Date: February 16, 2023

Topic: Caring Through Crisis

Date: March 2, 2023

Topic: Cultural Humility in Pediatric Care

# Additional Information

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NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

NHPCO Project ECHO session recordings and Key Takeaways:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/>

NHPCO Project ECHO Registration Link:

<https://nhpc.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UEIYNwjSli8QCBF>

For more information:

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