The Critical Role of Understanding and Respecting Culture in Palliative and End of Life Care: Our African American Patients

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Presentation Outline

1. **Culture:**
   The Significant Impact of Culture on the Care of the Seriously Ill Patient and Family
2. **The Southern African American Community**
   - Cultural Values
   - Healthcare Disparities
   - COVID-19
3. **My Calling: Developing Culturally-Based Healthcare Programs:**
   - Programs Developed By and For the Community

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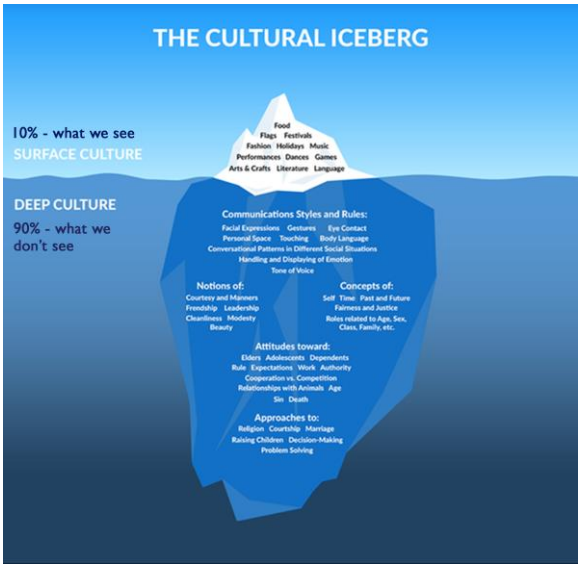
What is Culture?

Definition of *culture*

- The customary behaviors, customs, practices, attitudes, beliefs, core values and preferences of a racial/ethnic, religious, or social group.
- The characteristic features of everyday existence (i.e. way of life) shared by people in a place or time.



Hall's Model of Culture

Culture shapes our perception of illness

When we are ill: We perceive illness, suffering and dying through our own cultural lens.

Cultural Beliefs At End of Life

Religious, spiritual and cultural beliefs help people cope with the fear, stress, and grief associated with dying by providing a context of meaning and a structure of support.

Krauker et al., Am Geriatric Society, 20022002;50(1):182-190.

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1. Culture influences Preferences for care

- **Process of care**:
  - Type of medical/palliative care intervention
  - Degree of knowledge about prognosis
  - Level of family involvement in care decisions
- **Outcomes of care:**
  - Goals of care treatment
  - Degree of physical/emotional/mental compromise
  - Consideration of Advance Care Planning
  - Timing, process and place of death

* Cain, Surbone, **Elk** & Kagawa-Singer: Culture and Palliative Care: Preferences, Communications, Meaning and Mutual Decision Making. *Journal of Pain and Symptom Management*, *55* (5), 2018

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2. Culture influences Communication Patterns

- Talking about prognosis or death:
  - Taboo to talk about death in some cultures
  - There may be discordant understanding of the clinical situation (between patient/family and clinician)
  - Talking about a time till expected death not appropriate for some cultures.

* Cain, Surbone, **Elk** & Kagawa-Singer: Culture and Palliative Care: Preferences, Communications, Meaning and Mutual Decision Making. *Journal of Pain and Symptom Management*, *55* (5), 2018

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3. Culture influences meaning of suffering

- Physical and emotional pain may have a particular meaning
  - (e.g. test of faith in some Caribbean cultures.)
- Bereavement, rituals and expressions of grief vary by culture
  - (e.g. In Jewish culture, grieving period is divided into stages [7 days; 1 month; 1 year])
- In some cultures, group connectedness is of central importance
  - (e.g. “ubuntu” in sub-Saharan Africa). Group social practices.

* Cain, Surbone, **Elk** & Kagawa-Singer: Culture and Palliative Care: Preferences, Communications, Meaning and Mutual Decision Making. *Journal of Pain and Symptom Management*, *55* (5), 2018

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4. Culture influences decision-making process

- Depends whether individualism or communalism are primary values.
  - Individual autonomy stressed in US
  - May not be appropriate in other cultures.
- Authority given to clinicians varies by culture
  - Doctor is ultimate authority in some
  - God is ultimate authority in others
- Wishes about how want end of life:
  - In writing in US
  - Verbal communication preferred in other cultures.

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* Cain, Surbone, **Elk** & Kagawa-Singer: Culture and Palliative Care: Preferences, Communications, Meaning and Mutual Decision Making. *Journal of Pain and Symptom Management*, *55* (5), 2018

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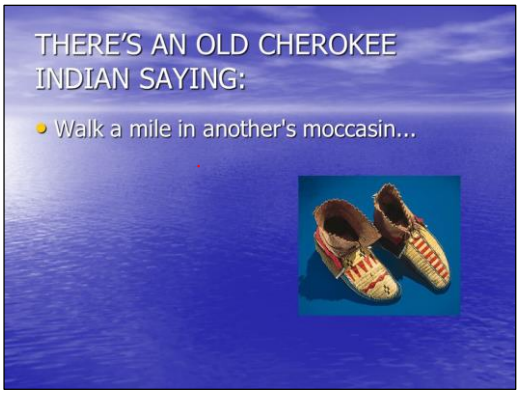
Intercultural-Sensitivity

- Being Aware of another's culture
- Understanding cultural differences
- Respecting cultural differences
- Valuing cultural differences



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- McDermott E, Selman LE. Cultural Factors Influencing Advance Care Planning in Progressive, Incurable Disease: A Systematic Review With Narrative Synthesis. *Journal of pain and symptom management.* 2018;56(4):613-636.
- 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):137-143.

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But, end of Life Care Values in the US

Historically rooted in values that represent the cultural and religious values of the white middle class.

BUT, these values that may not apply to other ethnic or cultural groups.

- Krakauer et. al., *J Am Geriatr Soc*, 2002; 50(1):182-190.
- Wicher CP, Meeker MA. *J Health Care Poor Underserved*. 2012;23(1):28-58

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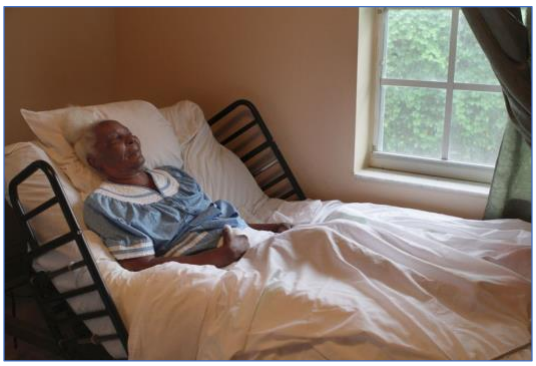
A lack of sensitivity to/lack of respect for cultural differences



may ***significantly compromise care*** for minority patients who are seriously ill or dying

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- 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):137-143.
- Kagawa-Singer M, Blackhall L. J. Negotiating Cross-Cultural Issues at the End of Life "You Got to Go Where He Lives". *Journal of American Medical Association* 2001;286(23).

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Culturally-based End of Life Care

- In the US, there were no End of Life Care programs developed ***to address the specific cultural values*** of a particular cultural group.
- But we knew this could be created.

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Krakauer EL, Crenner C, Fox K. Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatrics Society.* 2002;50(1):182-190.

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Racism and Slavery

- **Slavery/Racism**
  - History of centuries of slavery is strong,
  - Systemic and individual **racism** affect the daily life of the community

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Luth EA, Prigerson HG. Unintended Harm? Race Differences in the Relationship Between Advance Care Planning and Psychological Distress at the End of Life. *Journal of pain and symptom management.* 2018;56(5):752-759.

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Importance of Faith & Church

- **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

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Johnson KS, Elbert-Avila KI, Tulsky 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.

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Importance of Family and Community

- **Family** and **community** are the focus, rather than just on the individual

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Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. *Journal of pain and symptom management*. 2018;55(5):1408-1419.

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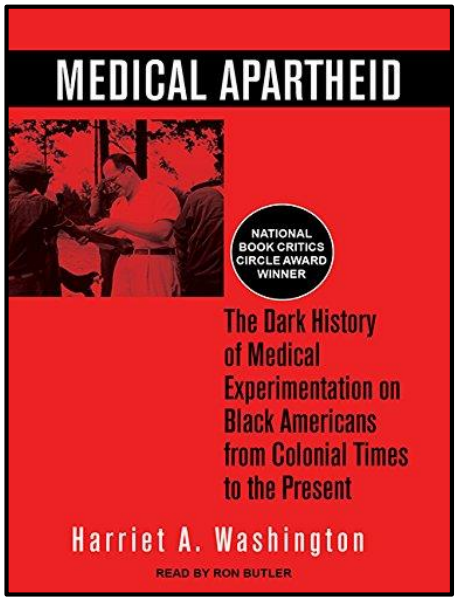
Lack of Trust in healthcare system



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Disparities in Care of African American at End of Life

- **Pain management:**
- Is not effective and equitable in African American elders
  - Pain is **not assessed** as well as in white patients
  - Pain is **not managed** well as in white patients
- **Results:**
  - Higher risk for **severe** pain & **complications**

- Mack JW, Paulk ME, Viswanath K, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Archives of internal medicine.* 2010;170(17):1533-1540.
- Chuang E, Hope AA, Allyn K, Szalkiewicz E, Gary B, Gong MN. Gaps in Provision of Primary and Specialty Palliative Care in the Acute Care Setting by Race and Ethnicity. *J Pain Symptom Management.* 2017;54(5):645-653.e641.

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Disparities in Care of African American at End of Life (2)

- **Goals of Patient Treatment**:
  - 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.

- 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.
- 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):137-143.

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COVID-19's Effect on the African American Community

100,000 + overall deaths in US (June 8th, 2020)

The latest available COVID-19 mortality rate for **African Americans** is:

- **2.2 times** higher than the rate for Latinos
- **2.3 times** higher than the rate for Asians,
- 3 times higher than the rate for Whites (higher in some states e.g., Kansas)
- **More than 200,000 African Americans (~1 in 2,000!!) died of COVID**

APM Research Lab, Mary 18th, 2020 www. Americanpublicmedia.org/research/

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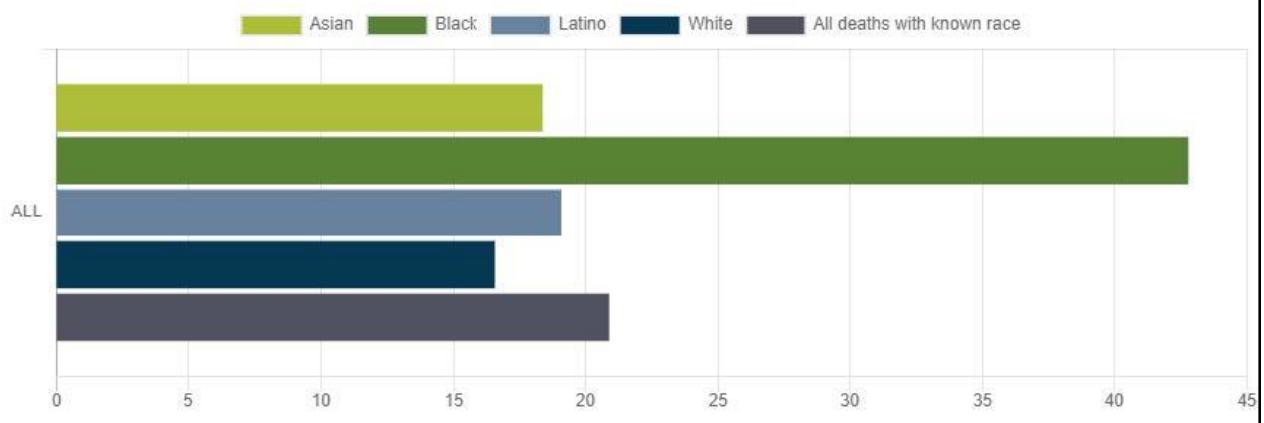
COVID-19 Deaths per 1000,000 people of each group

(All Ages) (Through May 11, 2020)

APM Research Lab, May 18th, 2020



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African American elders in nursing Homes

- **Nursing homes** where Black and Hispanic people make up a significant portion of the residents (*regardless of their location, no matter their size, no matter their government rating)*
- have been **twice** as likely to get hit by the coronavirus compared to those where the population is overwhelmingly white.

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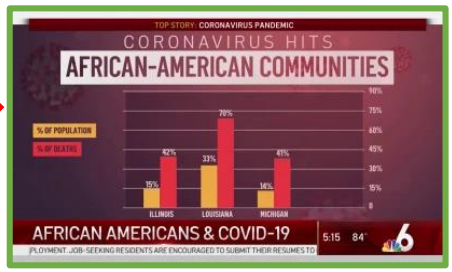
Understanding COVID-19 Risks and Vulnerabilities among Black Communities in America: The Lethal Force of Syndemics

Syndemics: Collusion of epidemics

- The racial health inequities in COVID have not emerged randomly nor passively;
- They are actively produced through anti-Black racism institutionalized within the American political system.



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Tonia Poteat et.al., Annals of Epidemiology, In Press, May 14, 2020

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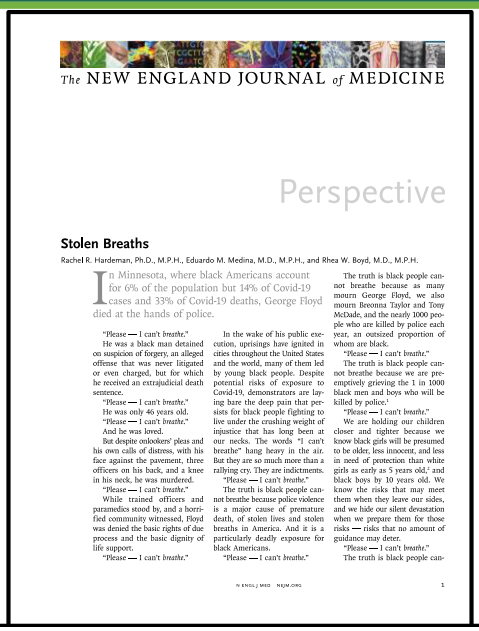
"Please ---- I can't breathe…"



The NEW ENGLAND JOURNAL of MEDICINE

Perspective

Stolen Breaths

Rachel R. Hardeman, Ph.D., M.P.H., Eduardo M. Medina, M.D., M.P.H., and Rhea W. Boyd, M.D., M.P.H.

In Minnesota, where black Americans account for 6% of the population but 14% of Covid-19 cases and 33% of Covid-19 deaths, George Floyd died at the hands of police.

"Please — I can't *breathe*."

He was a black man detained on suspicion of forgery, an alleged offense that was never litigated or even charged, but for which he received an extrajudicial death sentence.

"Please — I can't *breathe*."

He was only 46 years old.

"Please — I can't *breathe*."

And he was loved.

But despite onlookers' pleas and his own calls of distress, with his face against the pavement, three officers on his back, and a knee in his neck, he was murdered.

"Please — I can't *breathe*."

While trained officers and paramedics stood by, and a horrified community witnessed, Floyd was denied the basic rights of due process and the basic dignity of life support.

"Please — I can't *breathe*."

In the wake of his public execution, uprisings have ignited in cities throughout the United States and the world, many of them led by young black people. Despite potential risks of exposure to Covid-19, demonstrators are laying bare the deep pain that persists for black people fighting to live under the crushing weight of injustice that has long been at our necks. The words "I can't breathe" hang heavy in the air. But they are so much more than a rallying cry. They are indictments.

"Please — I can't *breathe*."

The truth is black people cannot breathe because police violence is a major cause of premature death, of stolen lives and stolen breaths in America. And it is a particularly deadly exposure for black Americans.

"Please — I can't *breathe*."

The truth is black people cannot breathe because as many mourn George Floyd, we also mourn Breonna Taylor and Tony McDade, and the nearly 1000 people who are killed by police each year, an outsized proportion of whom are black.

"Please — I can't *breathe*."

The truth is black people cannot breathe because we are preemptively grieving the 1 in 1000 black men and boys who will be killed by police.[1]

"Please — I can't *breathe*."

We are holding our children closer and tighter because we know black girls will be presumed to be older, less innocent, and less in need of protection than white girls as early as 5 years old,[2] and black boys by 10 years old. We know the risks that may meet them when they leave our sides, and we hide our silent devastation when we prepare them for those risks — risks that no amount of guidance may deter.

"Please — I can't *breathe*."

The truth is black people can-

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Our Dean's charge:

" When we improve health care for one at-risk group, we are ultimately generating better health outcomes for all

We must utilize this challenging and troubling moment to identify our opportunities to make an impact, and we must work to build something better every day. "

Selwyn Vickers, M.D., FACS
Senior Vice President for Medicine
Dean, School of Medicine
University of Alabama at Birmingham

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What can each of us do? So MUCH needs to be addressed

- Address/confront/dismantle **personal racism**
- Address/confront/dismantle **systemic racism**
- Address/confront/change personal and systemic **disparities in healthcare**

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My calling

- **To partner with underserved communities with the goal of:**

1. Finding out what **their** cultural values and preferences are
2. In partnership with those communities build **programs** that are based on their cultural values and preferences.
3. Build training programs to **train clinicians** in the cultural values and preferences of a particular underserved community. As a result:
   a. Enhance the knowledge of clinicians they understand such patients better.
   b. Increase clinicians' respect of the cultural values of the patient/family/community.
   c. Increase patients and families being heard and understood
   d. Provide care that is concordant with their values and wishes

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What I do:

- **As a researcher, I build and test models of care that:**
  - Can become **evidence-based** models of care
  - Can be replicated with **other underserved** communities
  - Reduce healthcare disparities
  - **Models that Work Towards Achieving Health Equity for All**

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In This Presentation, I'll tell you about two studies:

- Both of which were developed in *partnership* with members of the community.

Study 1: Beaufort SC

Study 1: Orangeburg, SC

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Study 1: Development of a Palliative Care tele-consult program

- Development of a Palliative Care tele-consult program that respects the unique cultures of
  - African American
  - White
  - Rural
  - Southern
  - Elders

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Study Location: Beaufort, SC

- High rate of poverty
- High rate of unemployment
- High rates of health disparities
- Deep history of slavery

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Our Study's Guiding Principles

1. Full Community Partnership
(using CBPR: Community Based Participatory Research)

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Community Based Participatory Research:
1. Convene a Community Advisory Group (CAG)

Members of the community who:

- Are from same group as group you serve.
- Have experience with the issue you're addressing.
- Leaders and gatekeepers and well-respected members.
- Hospital or hospice staff.
- "Regular" folk.

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Community Based Participatory Research:
2. Community involvement *throughout*

- *Before* you start
- *During* each step
- *After* each step

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Community Based Participatory Research
3. Listen to your community members

- They know their community best
- Listen to and *hear* what they say
- Follow their advice *(even if it's not what you had planned)*
- It takes time and genuine respect to build & establish trust



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Evidence-Based Palliative Care





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Study Design:

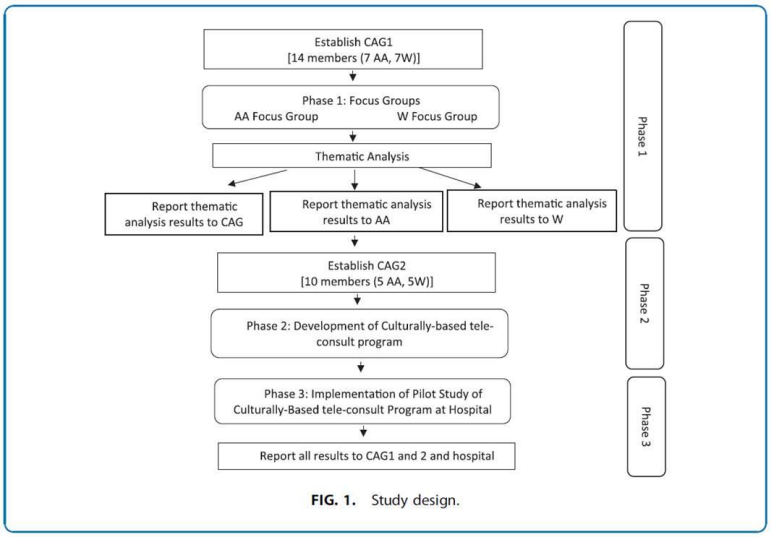

FIG. 1. Study design.

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Elk R, Emanuel L, Hauser J, Bakitas M, Levkoff S. Developing and Testing the Feasibility of a Culturally Based Tele-Palliative Care Consult Based on the Cultural Values and Preferences of Southern, Rural African American and White Community Members: A Program by and for the Community. *Health Equity.* 2020;4(1):52-83.

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Phase 1: Focus Groups

CAG Recommended Separate Focus Groups

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Phase 1: Focus Group Questions

Care that their loved ones received (+ & -):

1. Preferred Care/Treatment
2. Communication with the Provider
3. Decision-Making
4. Trust in Hospital/Hospice and Care System

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Phase 1: Analysis of Focus Group Data

- All sessions were audio-taped & transcribed
- Systematic thematic analysis; coded categories
- Themes emerged (examples):
  - Poor physician communication
  - Sharing of prognosis
  - Referral to nursing homes/hospice
- For each theme: was it same/different for the two ethnic groups?

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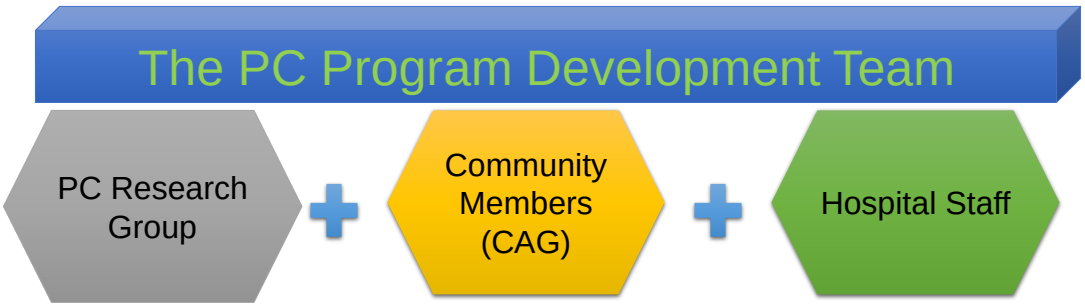
Phase 2: Program Development Principles: Equal Participation



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How are culturally- based preferences incorporated into an evidence-based PC program?

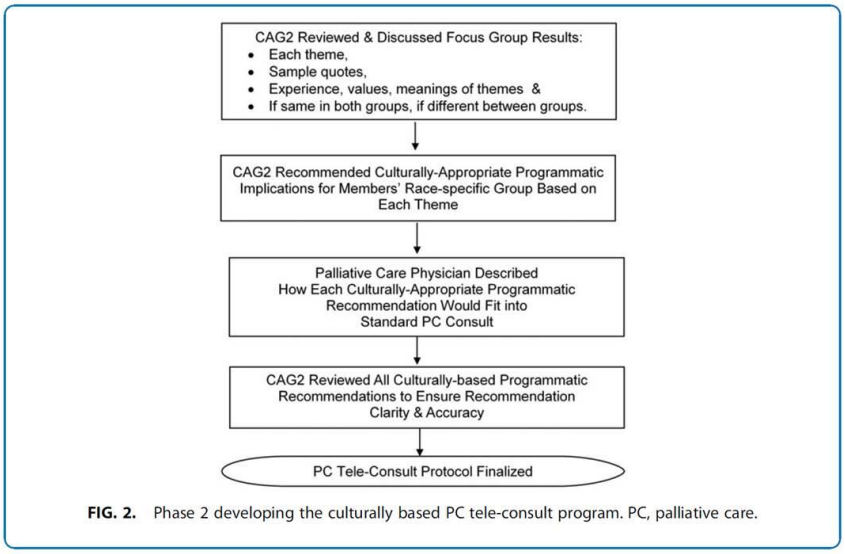

FIG. 2. Phase 2 developing the culturally based PC tele-consult program. PC, palliative care.

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This phase took TWO YEARS!!

Community Advisory Board members *rarely* missed the monthly meetings.

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Themes and Recommendations

Table 5. Theme: Religion, Church, and Pastor

	Phase 1: focus groups		Phase 2: recommendations	
Sub-themes	AA	White	AA	White
(A) Religion is our source of comfort and the church is at the center of our lives	"My son in law is a minister, so he called … and I asked him to please pray for him (patient) over the phone. So I put the phone to his ear, and I put the speaker on so we could both hear, and he prayed, and when he finished, my husband said 'Amen' right along with him and that was the last word he ever said. After that prayer he never said another word." "And so because you encounter things and people will question you as to how you go through it or how you handled it because it really has nothing to do with you it has to do with your faith … because it is rough. You know, because it's someone you love and even though we know what the Word says about it, you really hate to part with that person." "She (sister) said, 'I mean you're tired' and she said, 'You just go ahead with the Lord.' And my dad opened his eyes, and my sisters and I were standing around the bed, and he opened his eyes and he turned around and looked at all of us. He took that last breath and just went right on to sleep."	X	(1) Religion is the source of all of comfort, a key value, and it's the perspective from which AAs view the world. Therefore, in all PC physician interactions with AA patients, recognize and respect that this is an integral part of all that is said and done.	X
(B) Pastor helped accept end-of-life reality	"And at Sabbath, they was in service at church and my pastor was there … and I just started screaming that afternoon. I mean just boo-hoo, crying like someone was killing me, and he came over to me and he prayed. And he said, 'God said to tell you that you've done all that you can do. So you've done everything you could do for him.'" "Those last two weeks, I mean he just went down, and when I had—my daughter and son-in-law had gone to a football game and so—my son-in-law is a minister, so he called after they got back from the game and I asked him to please pray for him over the phone. So I put the phone to his ear, and I put the speaker on so we could both hear, and he prayed. And when he finished, my husband said 'Amen' right along with him, and that was the last word he said. And that was on a Friday night, and the following—not the next Saturday, but a week from that, is when he passed. But that was the last word he said—'amen.' After that prayer, he never said another word."	"I was in denial … and disconnected about it. But … that's when I got my pastor involved." "But when our pastor came and stood in the doorway and said, 'P. peace be with you,' it had an impact."	(1) Pastors are the key to helping us understand prognosis and impending death. If the issues of prognosis arises, suggest that they may want to invite their pastors to the discussion of prognosis. Then ask the name of the pastor and say you would welcome them to the meeting.	(1) Pastors are the key to helping us understand prognosis and impending death. If the issues of prognosis arises, suggest that they may want to invite their pastors to the discussion of prognosis. Then ask the name of the pastor and say you would welcome them to the meeting.

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Physician Guidelines/Protocol

Role of Religion and Church	
African American	**White**
Recognize importance of pastors, especially in discussing prognosis. Invite pastor to next meeting if discussing prognosis.	
Recognize importance of religion, source of comfort, knowledge, a guide for all things	Recognize church members are a source of support. If support needed, ask if a church member can assist; ask name of church member and discuss how they can provide support.

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Phase 3: Did it work?

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Community Advisory Group Members met patients first.

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How satisfied were the patients & family with the Tele-Palliative Care Physician?

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
• The way the PC doctor included the patient and family in the decisions of treatment and care?				**14**	**86**
• The way the PC doctor respected the dignity of the patient and family in the consult?					**100**
• Emotional support provided by the PC doctor to the patient and family in the consult?					**100**
• Information given by the PC doctor about how to manage the patient's symptoms?					**100**

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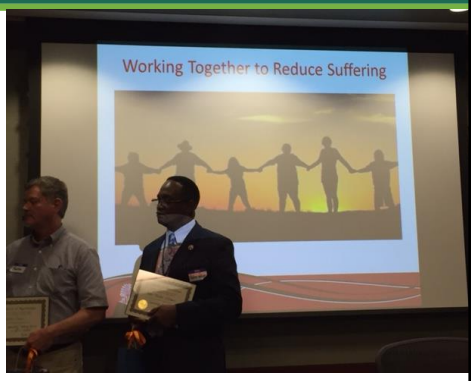
Together we created a Palliative Care program that:

- Is culturally-appropriate for:
  - Rural Southern
    - African American elders & family
    - White elders & family
- Most patients/families accepted
- All families who accepted were very satisfied with tele-palliative care consult
- Community has “ownership”



The first such program in the US.

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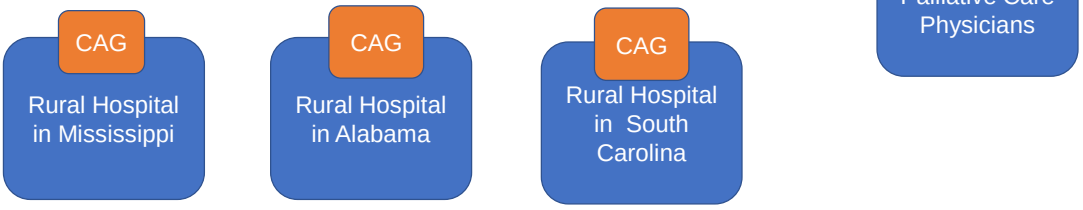
Is it Effective? NIH 5 year multi-million grant

- Randomized Control Trial comparing
  - Standard Medical Care **+** Palliative Care Telehealth-Consult
  - Standard Medical Care



If this culturally-based palliative tele-consult is found to be effective (in reducing suffering in patients, increasing quality of life and reducing caregiver burden) → New Evidence-based Clinical Guidelines

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Study 2: Development of Training for Physicians

Creating a series of training videos for healthcare providers on how **African Americans** would like healthcare providers to communicate with and treat African American elders who are seriously ill.

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Developing Culturally Relevant Videos (1)

Community Advisory Group

- 14 members
- Pastors
- Family of patient
- Hospital Staff

Meetings:

20 meetings over several months

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Developing the Culturally Relevant Videos (2)

Step 1:

Reviewed state-of-the-art videos on effective communication with patients with serious illness

Step 2:

CAG determined some communication principles did not meet the cultural values of Southern rural African American communities.

Step 3:

CAG chose to make new videos.

Step 4:

Video themes chosen were based on 3 themes that emerged from the focus groups

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Developing the Culturally Relevant Videos (3)

Step 5:

Once a message was chosen, the CAG brainstormed a scenario/skit in which they highlighted this message.

Step 6:

Once a scenario was chosen, the CAG developed a script until group agreed.

Step 7:

CAG members were chosen to play out the roles.

Step 8:

The group practiced each scenario.

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Developing the Culturally Relevant Videos (4)

- Step 9: A professional filmmaker filmed each video.
- Each 2-3 minute video took at one to 1-1.5 ***hours*** to film.



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Title of Video Series

The Community Advisory Group chose this title for their video series:

Communities Speak to Healthcare Providers: Conversations with African Americans at End of Life

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Training Program Incorporated

A 3-hour training program was developed by training experts to help healthcare professionals debrief and learn from the videos:

- Based on adult learning principles
- Self-Insight
- Relevance to clinical experience

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This Video +Training Program is the FIRST:

- To the best of our knowledge, the ***first*** in USA that is:
  - Based on what members of a particular culture value and request.
  - Geared specifically towards African American rural Southern culture.
  - A model that can be replicated for other cultures.

- How is this model different?
  - Usually healthcare providers provide training to patients/families.
  - In this model, the patients/families provide training to healthcare providers.

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Has this been effective?

Clinicians

- In enhancing Palliative Care clinician knowledge of cultural values of African Americans with serious illness? **Yes**
- In enhancing confidence of Palliative Care clinicians in changing practice? **Yes**
- In changing practice? **Yes**

African American Patients

- Confidence in clinicians (Geriatricians) pre and post training **July-Sep**
- Trust in clinicians (Geriatricians) pre and post training **July-Sep**

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There's so much we have to do to achieve health equity

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With deep appreciation to an incredible team

Orangeburg CAG

Orangeburg Pastors

Filmmaker: Roni Nicole

Karen Jones, MPH, PhD
Study Manager

Gloria Eisemome, MBChB, PhD
Graduate Assistant

Roman Johnson, MA, PhD student.
Graduate Assistant

Andrea Gibson, MPH
Focus group facilitator

Akeen Hamilton, MA
PhD student
Summer Study Manager

Alvin Reaves, MD
Palliative Care Physician

Ronit Elk, PhD
Study PI

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