

# Paying Attention to Culture: Lessons from the Rural South

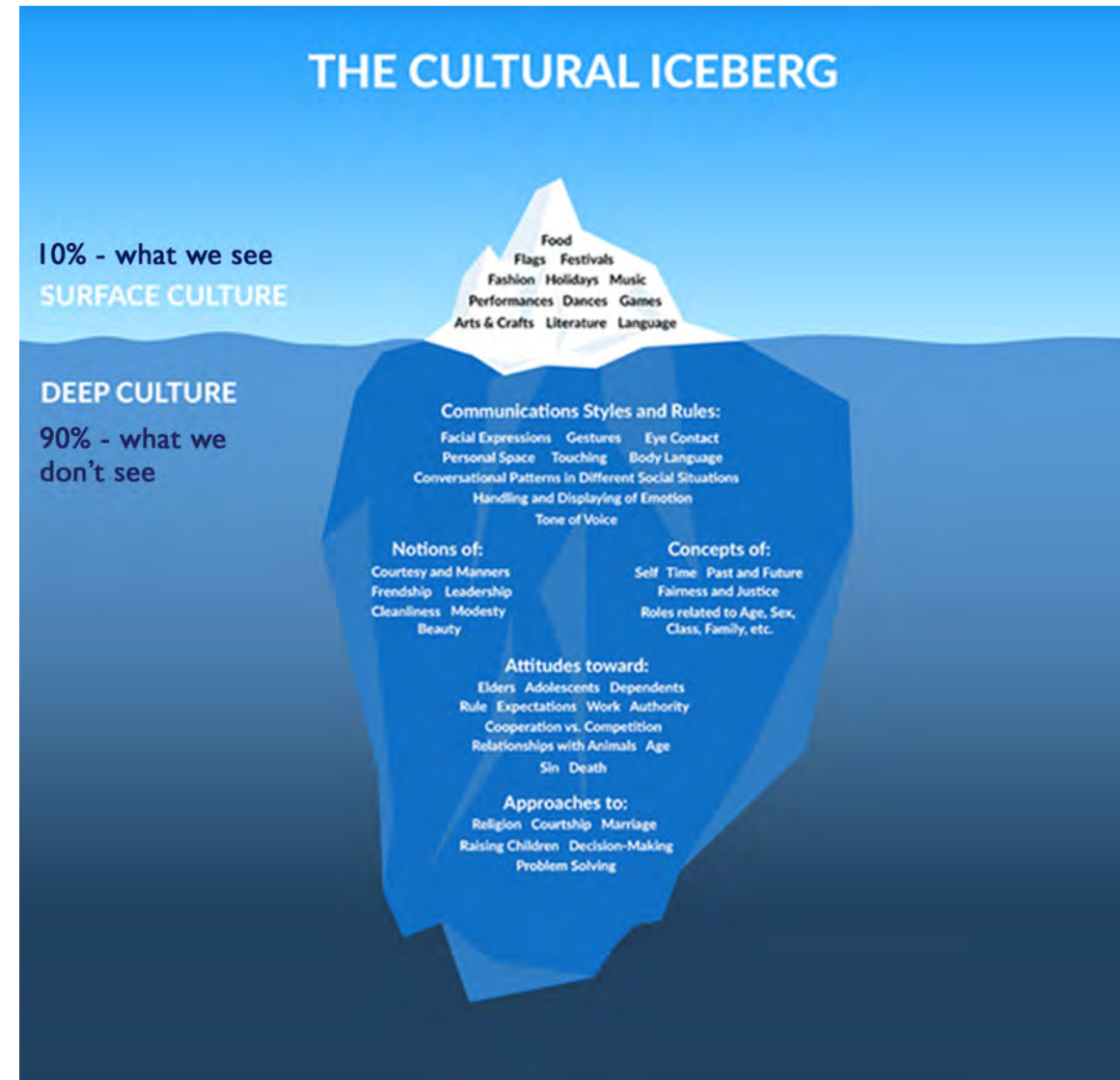
*Programs by the Community for the Community*

Ronit Elk, PhD

# 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.
- ❑ [The set of shared attitudes, values, goals, and practices that characterizes an institution or organization]



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 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.

# How does Culture impact palliative care?\*

1. Preferences for care
2. Communication patterns
3. Meanings of suffering
4. Decision-making process

\* 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

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

# 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.



# 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



# 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.



# End of Life Care Values in the US

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

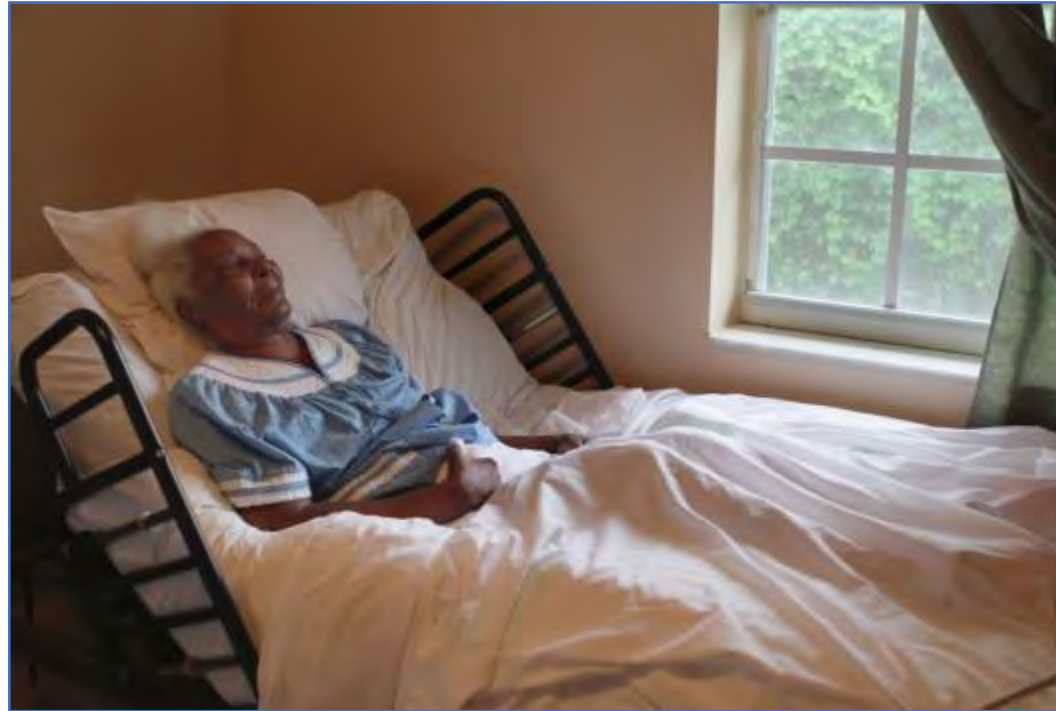


Krakauer et. al., *J Am Geriatr Soc*, 2002; 50(1):182-190.  
Wicher CP, Meeker MA. *J Health Care Poor Underserved*. 2012;23(1):28-58

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



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



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

# The need to provide high-quality, culturally-competent care is a national priority

The lack of culturally-competent end of life care has been referred to as a significant public health crisis in the US

(Periyakoil, 2016)



# What is Cultural Competence in Healthcare?

- Sensitivity to a patient/family's cultural:
  - Attitudes
  - Beliefs
  - Context
  - Decision-making Style
  - Environment



Kagawa-Singer, M. & Blackwell, LJ. [JAMA](#). 2001 Dec 19;286(23):2993-3001. Negotiating cross-cultural issues at the end of life: "You got to go where he lives".

# What is Cultural Competence in End of Life care?

- Sensitivity to a patient/family's cultural:
  - **Attitudes** (e.g. to hearing prognosis, discussion of death/dying)
  - **Beliefs** (e.g. spiritual beliefs re meaning of death, miracles)
  - **Context** (e.g. historical, political context of their lives)
  - **Decision-making Style** (e.g. Patient-centered or family-centered)
  - **Environment** (e.g. Resources available in patient/family's life, neighborhood)

Kagawa-Singer, M. & Blackwell, LJ. [JAMA](#). 2001 Dec 19;286(23):2993-3001. Negotiating cross-cultural issues at the end of life: "You got to go where he lives".

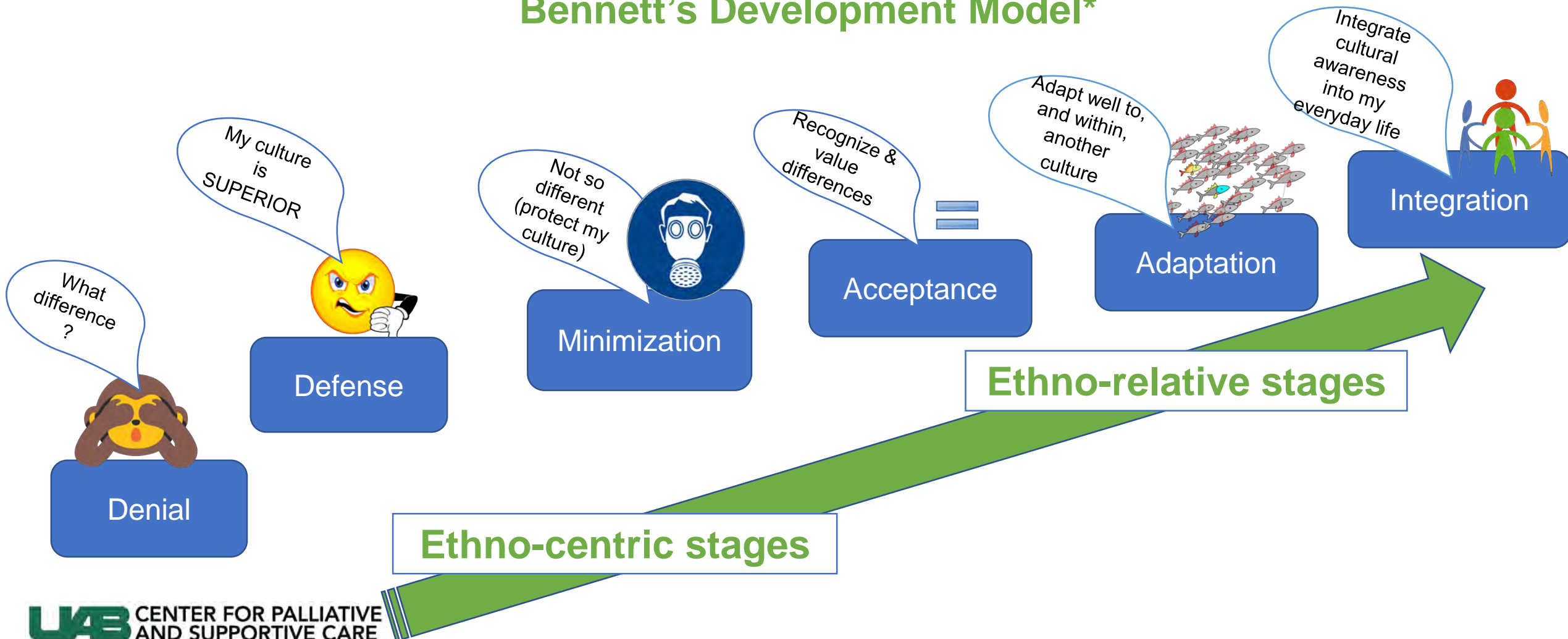
# What is Intercultural-Sensitivity?

- Awareness of anothers' culture
  - Understanding cultural differences
  - Respecting cultural differences
  - Valuing cultural differences
- 
- Think how important this is in the healthcare setting
  - Think how you'd feel if it was ***your*** cultural value that isn't valued/respected?



# Developing Intercultural Sensitivity

## The Process of Development of Intercultural Sensitivity Bennett's Development Model\*





# In the US Culturally-based Palliative Care Is not widely Available (yet)



**But it certainly can be developed !!!**

# How do we build culturally-based programs?

1. Establish true *equal* partnership with cultural groups (communities)
2. Build trust
3. Ask! (about cultural values and preferences.)
4. Listen and (really) hear (not from your culture's perspective)
5. Value and respect what you hear
6. Record what is said & check with the group that it's correct.
7. Design programs that meet the culturally-based preferences & values of that community
8. Implement community-developed programs

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

- Both of which followed these 8 steps.
- Both of which were developed in *partnership* with members of the community.



Study 1: Beaufort SC



Study 2: Orangeburg, SC

# 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



# Study 2: Development of Training for Physicians

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



# Goals of Study 1: Culturally-Based Tele-Palliative Care

1. To develop a Palliative Care Consult Program:
  - That is a cultural fit for rural Southern African American and Whites
  - In collaboration with the community.
2. To deliver it:
  - In a rural hospital
  - Via telemedicine.
3. To determine the Program's:
  - Feasibility
  - Acceptability by the patients and family.
  - Family Satisfaction

# Study Location: Beaufort, SC



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



# Our Study's Guiding Principles

1. Evidence-based Palliative Care practice
2. Community Partnership  
(using CBPR: Community Based Participatory Research)





# Evidence-Based Palliative Care



# 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.



# Community Based Participatory Research:

## 2. Community involvement *throughout*

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



# 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



# Study Design:

Before, During, and After each Phase:  
Community Advisory Group

## Phase 1

Community  
Focus  
Groups

## Phase 2

Community  
Input into  
Palliative  
Care  
Program

## Phase 3:

Implementation of  
PC Consult  
Program in  
Community  
Hospital

# Phase 1: Focus Groups

## CAG Recommended Separate Focus Groups



# 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

# Phase 1: Analysis of Focus Group Data

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



# Phase 2: Program Development Principles: Equal Participation

## The PC Program Development Team

PC Research  
Group

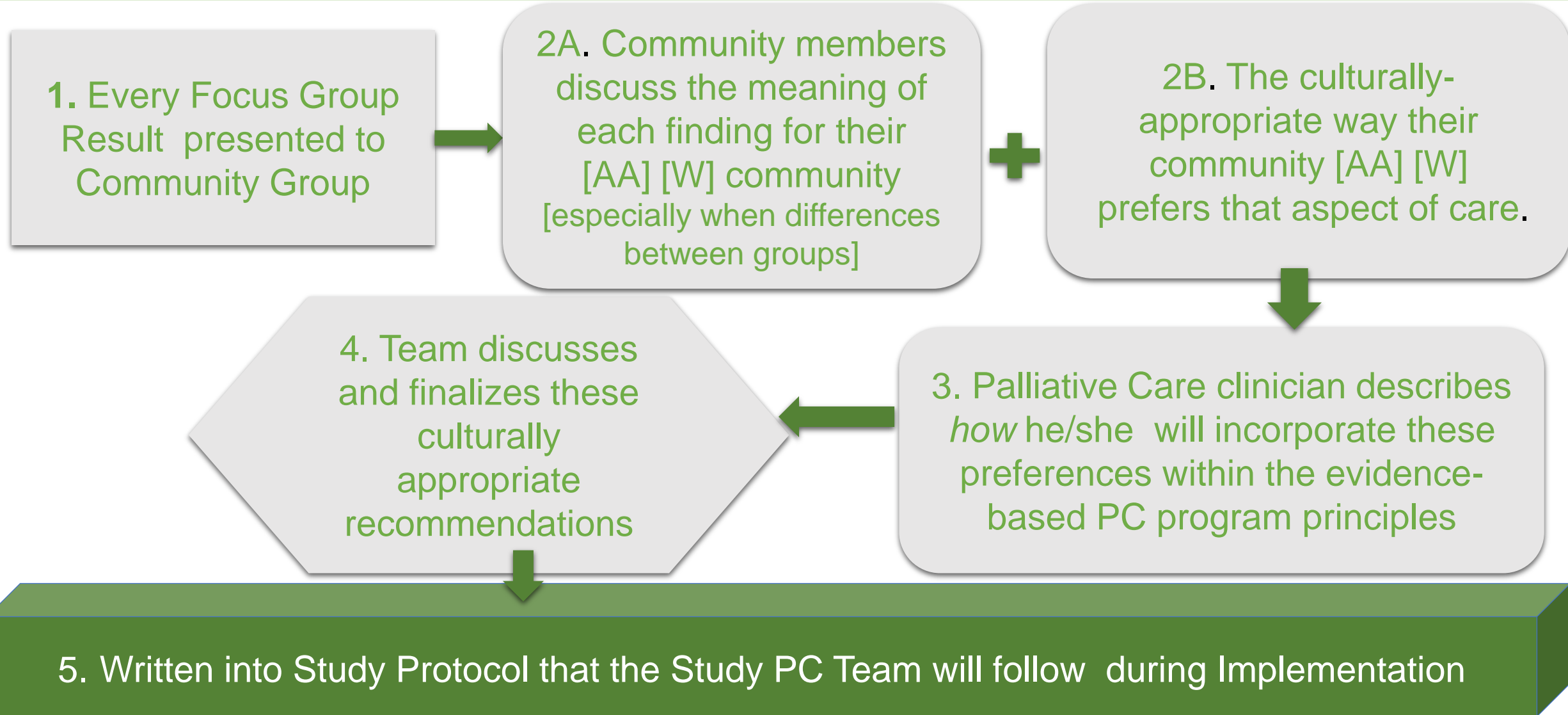


Community  
Members  
(CAG)



Hospital Staff

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



# This phase took TWO YEARS!!

Community Advisory Board members *rarely* missed the monthly meetings



# Example of Programmatic Implications That Are *Same* For White and African:

## Physician Communication

<b>Phase 1:</b> Themes from <b>Both</b> Focus Groups	<b>Phase 2:</b> Programmatic Implications for All Patients
Many in both groups reported experiences of poor and/or rude physician communication	Palliative Care Physician should never be rude or discourteous to patient and family

# Programmatic Implications That Are *Different* Between the Two Groups

## Discussing Hospice (African American perspective)

<b>Phase 1:</b> Themes from African American Focus Group	<b>Phase 2:</b> Programmatic Implications for African Americans patients and family
We take care of our own.	Do not raise issue of hospice
The family takes care of our loved one in our home.	If family discusses need for assistance/overburdened: Explain re help at home
Hospice equals death	Stress that hospice staff are <i>not</i> there to take over, only to assist as needed.

# Programmatic Implications That Are *Different* Between the Two Groups:

## Advance Care Planning (African American perspective)

<b>Phase 1:</b> Themes from African American Focus Group	<b>Phase 2:</b> Programmatic Implications for African Americans patients and family
We know what he/she wants. She already told us	Do not raise written ACP
We'll do whatever he/she wants us to do	Respect family wishes
Why put in writing?	After building trust, ask what guidance/instructions patient asked family to follow. Follow those requests.

# Phase 3: Did it work?



Photo credit: Essentia Health



# Community Advisory Group Members met patients first



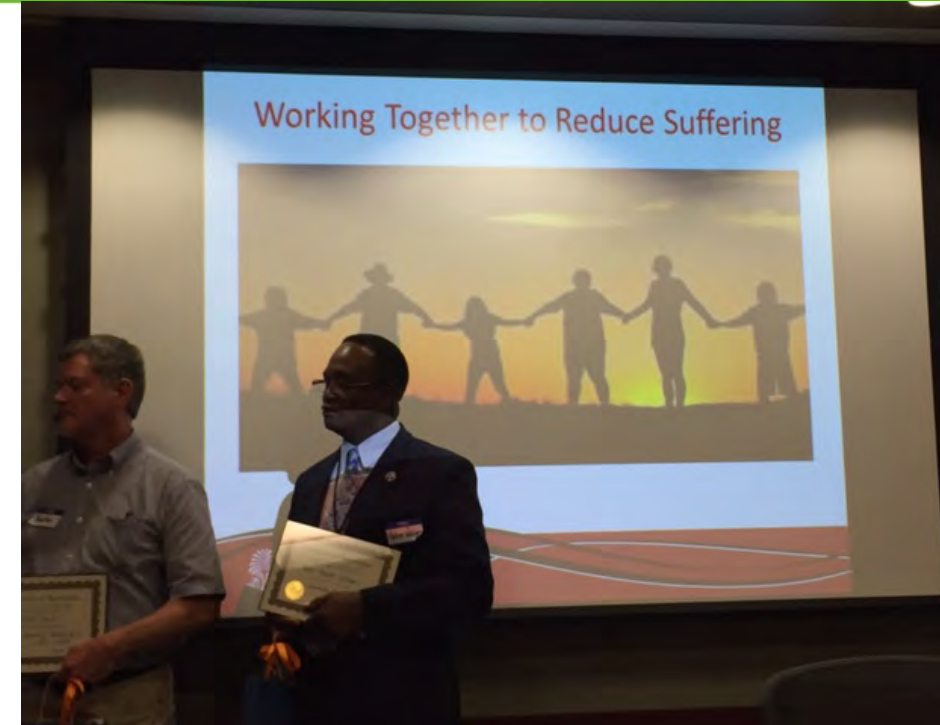


# How satisfied were the patients & family with the Tele-Palliative Care Physician?

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
<ul style="list-style-type: none"> <li>The way the PC doctor included the patient and family in the decisions of treatment and care?</li> </ul>				14	86
<ul style="list-style-type: none"> <li>The way the PC doctor respected the dignity of the patient and family in the consult?</li> </ul>					100
<ul style="list-style-type: none"> <li>Emotional support provided by the PC doctor to the patient and family in the consult?</li> </ul>					100
<ul style="list-style-type: none"> <li>Information given by the PC doctor about how to manage the patient's symptoms?</li> </ul>					100

# 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**

# Can be replicated in other cultures

- We're replicating Phase 1 (Focus groups guided by Community Advisory Group) of this study in Kumasi, Ghana

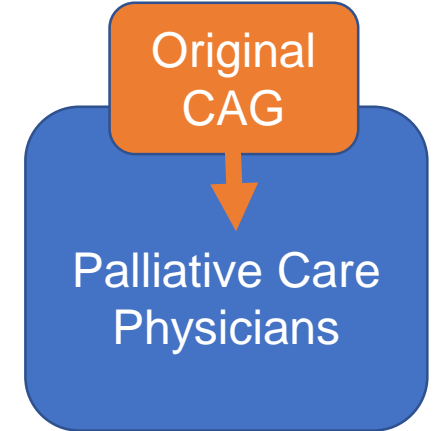
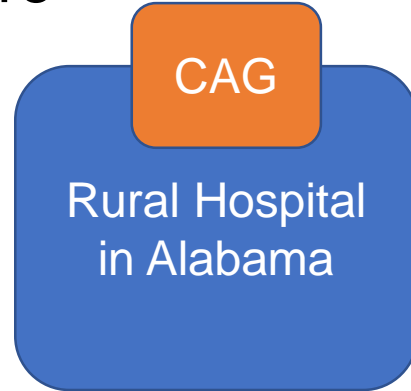


- We are funded to replicate Phase 1 (Focus groups guided by Community Advisory Group) of this study in San Juan, Puerto Rico



# NIH R01 (5 year) 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**

# Funding for this study is gratefully acknowledged

- ASPIRE-II, University of South Carolina
- SCTR, Medical University of South Carolina
- NIA, 1R21AG046772-01A1

# Study 2: Development of Training for Healthcare Providers

Creating a training program for healthcare providers on how *members of this culture* would like healthcare providers to communicate with and treat African American elders who are seriously ill.



# Study takes place in Orangeburg, SC



- **Population:**
- 13,964 over 8 sq. miles
- Live in rural areas: 66%
- **Ethnic group:**
  - African American: 63%
  - White: 35%
  - Hispanic: 1%



- **Income:**
  - Median : \$30,552
  - Per capita : \$15,263
  - Below poverty line: 30.4%
- **HBCUs:**
  - Claflin University, oldest HBCU in SC (1869)
  - South Carolina State University (1896)

# Goals of Study 2

- To create a training program for healthcare workers who treat rural Southern African American patients with serious illness.
- To explain this community's:
  - Cultural values
  - Cultural preferences
  - Culturally appropriate communication methods



# Study Design:

## Community Based Participatory Research (Orangeburg, SC)

Phase 1:  
Community  
Advisory  
Group  
Advice

Phase 2:  
Focus  
Groups

Phase 3:  
(a) Determination of  
Method of Training  
(b) Development of  
Videos

Phase 4:  
Development  
of Training  
Component

Phase 5:  
(To be  
done)  
Testing of  
Efficacy

# Focus Group Analysis



## Thematic Analysis: Examples of themes that emerged

Theme 1:  
Family and  
community is  
key

Theme 2:  
Never give bad  
news to a  
patient when  
patient is alone

Theme 3:  
Doctors need  
to convey hope  
(regardless of  
prognosis)

Theme 4:  
Treat us like  
you treat your  
own

# Phase 3: Developing Culturally Relevant Videos

## Community Advisory Group

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

## Meetings:

20 meetings over several months



# Phase 3: Developing the Culturally Relevant Videos

## 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



# Phase 3: Developing the Culturally Relevant Videos

## 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.



# Phase 3: Developing the Culturally Relevant Training

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



# 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**

# Phase 4: Training Program Incorporated

Later, a training program was developed by training experts to help healthcare professionals debrief and learn from the videos:

- Dealing with emotions each video raises
- Understanding, respecting the cultural values and preferences
- Determining relevance to clinical practice





# 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.

# Next Steps: Evaluation & Testing

## 1. Short-Term Evaluation

- Do the providers find it helpful?
- Does it enhance provider confidence in understanding the cultural wishes?



## 2. Grant (RCT) to determine its efficacy (compared to other method)

- Physician perspective: Does it enhance confidence of provider in understanding the cultural wishes?
- Patients and Family Perspective: Do African American patients feel their culture, values are respected and their preferences adhered to?



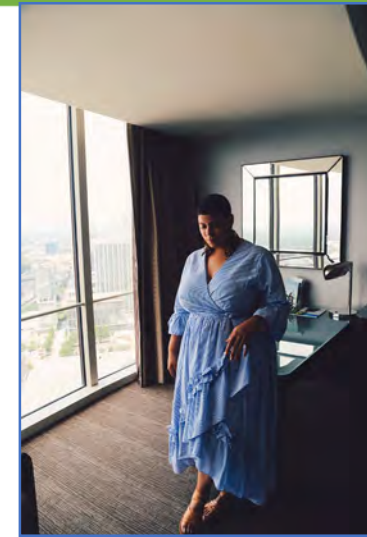
# With deep appreciation to an incredible team



Orangeburg CAG



Orangeburg Pastors



Filmmaker: Roni Nicole



Karen Jones, MPH,  
PhD  
Study Manager



Gloria Eisemome,  
MBChB, PhD  
Graduate Assistant



Roman Johnson, MA,  
PhD student.  
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Andrea Gibson, MPH  
Focus group  
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Akeen Hamilton, MA  
PhD student  
Summer Study Manager



Alvin Reaves, MD  
Palliative Care Physician



Ronit Elk, PhD  
Study PI

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