


Recognizing the Importance of Culture and the Lived Experience of Racism in The Care of our African American Patients and Their Families


Ronit Elk, PhD



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PRESENTATION OUTLINE

1. Understanding Culture
2. The Impact of Culture on the Care of the Seriously Ill Patient and Family
3. Understanding our African American patients
4. Developing Health Care Programs for patients with serious illness or at E-o-L based on our patients' culture and their lived experience
5. What can you (as a clinician/researcher/educator) do?



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CULTURE SHAPES OUR PERCEPTION OF ILLNESS


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



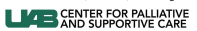

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CULTURE IMPACTS SERIOUS ILLNESS

- **Preferences for Care**
 - Type of care received
 - Level of family involvement
- **Outcomes of Care:**
 - Degree of physical/emotional compromise
 - Timing, process & place of death
- **Communication Patterns**
 - Talking about time to death
- **Meaning of Illness**
 - Meaning of illness or suffering
- **Decision Making**
 - Ultimate authority is physician/God.




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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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.
Widner CP, Meeker WA. J Health Care Poor Underserved. 2012;23(1):28-58

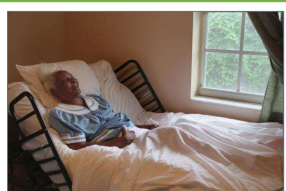
BUT these values that may not apply to other ethnic or cultural groups






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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



6

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)



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HOW CAN WE PROVIDE CULTURALLY CONCORDANT CARE TO OUR AFRICAN AMERICANS PATIENTS?

Understand & Respect

- The Cultural Values and Care Preferences &
- The Lived Experiences of Systemic Racism Of our African American patients.

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I AM NOT AFRICAN AMERICAN



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IMPORTANCE OF FAITH AND CHURCH (1)

By many measures, African Americans are more religious than whites and Latinos

% of ___ who ...	Blacks	Hispanics	Whites
... say they believe in God with absolute certainty	83%	59	61
... say religion is very important	75	59	49
... say they pray daily	73	58	52
... say they attend religious services at least once a week	41	39	34

Note: Whites and blacks include only non-Hispanics. Hispanics can be of any race. Source: 2014 U.S. Religious Landscape Study, conducted June 4-Sept. 30, 2014. PEW RESEARCH CENTER


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U.S. Religious Landscape Survey: Religious Beliefs and Practices. Washington, D.C. : Pew Research Center; 2014

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IMPORTANCE OF FAITH & CHURCH (2)

- For those African Americans who believe in God:
 - Religion and church is fundamental to all being, knowledge, life's vision
 - Pastor's role is key
 - God is in charge (including when a person dies)
 - Belief in hope and miracles is very prevalent (85%)




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Johnson KS, Elbert-Avila K, Tulskey 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**

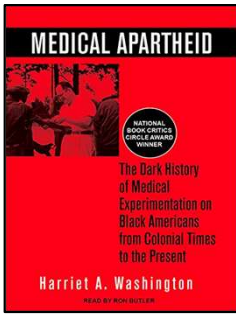


Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. *Journal of pain and symptom management*. 2018;55(5):1408-1419.

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LACK OF TRUST IN HEALTHCARE SYSTEM



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THERE'S MORE! DISPARITIES IN CARE OF AFRICAN AMERICANS (1)

- **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 of medical care received near death. Archives of Internal Medicine. 2010;170(17):1533-1540.

• Chung E, Hopp AA, Allyn K, Szaboewicz E, Gary B, Gong M. 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):940-953.e941.

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DISPARITIES IN CARE OF AFRICAN AMERICAN AT END OF LIFE (2)

- **Goals of Care:**
 - Less often discussed by doctors
 - Less often recorded by doctors in the patient's records
 - Even when African Americans have written goals of care in the patient's records, more 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.

• Rhoades 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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RACISM AND SLAVERY

- **Slavery/Racism**
 - History of slavery and racism is so that the memory is in DNA for generations.
 - Systemic and individual **racism** effects the daily life of the community, resulting in serious trauma.

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SYSTEMIC RACISM IS A PUBLIC HEALTH CRISIS

NIHCM Systemic Racism Is a Public Health Crisis: Impact on the Black Community

DATA INSIGHTS

What is systemic racism?

Systemic racism: the way policies & practices of organizations or systems disadvantage some populations, while advantaging others, creating different outcomes for different racial groups

Among Black Americans, systemic racism has led to long-standing inequities and striking disparities linked to COVID-19.

COVID-19 highlights the link between racism and health

- Black individuals account for 13% of the US population
- And 23% of COVID-19 related deaths
- Black people are dying from COVID-19 at a rate 2.4x higher than White people

What makes the Black community more at risk for COVID-19?

- Higher rates of pre-existing health conditions
- Over-represented in frontline & essential worker jobs
- Unequal access to quality health care & insurance coverage
- More likely to live in overcrowded neighborhoods

Long-standing inequities caused by systemic racism exacerbate health impacts

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HEALTH CONSEQUENCES OF SYSTEMIC RACISM

Long-standing inequities caused by systemic racism exacerbate health impacts

Food Security	Black individuals receive 2x less food to eat than White people
Income	Black individuals make up 40% of the homeless population
Health	The net worth of a typical White family is 20x greater than of a Black family
Education	80% of Black students receive a 4 year degree vs 64% of White students
Home Ownership	Black Americans are 60% less likely to own a home than White Americans

How does systemic racism and the stress of racism impact health?

Systemic racism leads to health impacts through the following pathways:

- Health Impacts: This happens due to the health disparities that exist.
- Adversity Load: Adversity load is the cumulative burden of stressors that impact health.
- Chronic Stress: Chronic stress is the long-term response to stressors that impact health.
- Exacerbated Health Disparities: This happens due to the health disparities that exist.

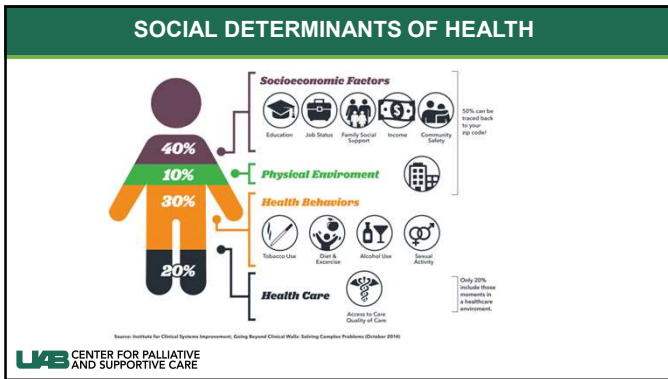
Synopsis of resulting health disparities

Hypertension	42%
Diabetes	30%
Obesity	38%

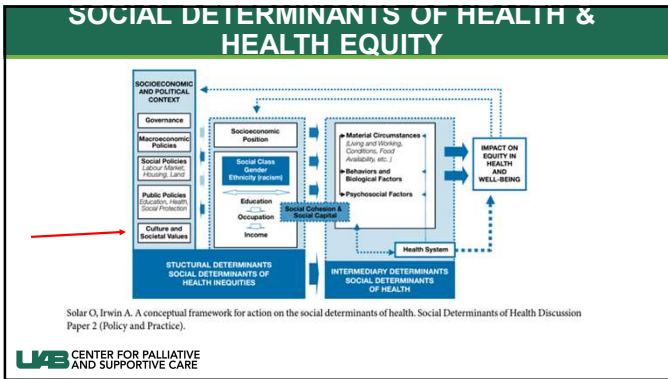
Relative Mortality

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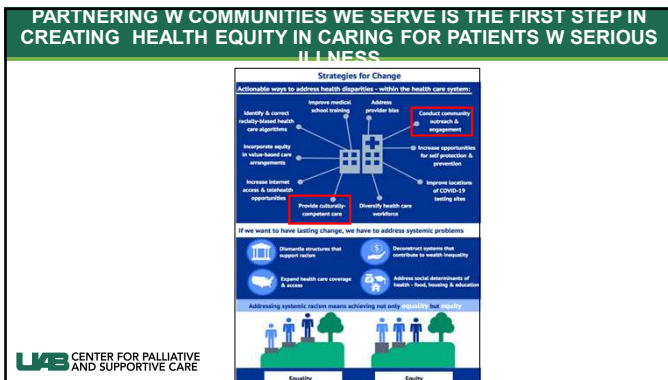
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COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)

- CBPR is an orientation to research that emphasizes:
 - Mutual respect between partners (usually academia and community)
 - Building capacity within the community
 - Balancing research/program building & social action

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IN CBPR: CHANGE IN BALANCE OF POWER

In academia/medicine we're typically the experts and the communities the recipients of our knowledge

- But in CBPR community members participate *equally* in the research/program development process
- They share their knowledge & experience on:
 - All aspects of the research/program development process
 - Make recommendations for solutions
- We listen to these recommendations
 - These form the healthcare research/program being created
 - Outcome benefits the community

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STUDY 1:

- Aim of Study:
 - Using CBPR approach:
 - Partner with Southern, rural Community Members
 - African American and White
 - To create a Palliative Care Consult via Telehealth
 - That is culturally concordant with cultural and religious values of
 - Southern, rural, older adults with serious illness
 - African Americans and Whites

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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 provide care to.
- Have experience with the issue you're addressing.
- Leaders and gatekeepers and well-respected members.
- Hospital or nursing home staff.



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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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THIS STUDY TOOK OVER 3.5 YEARS!!

Community Advisory Board members *rarely* missed the monthly meetings



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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
- When we pilot tested this in the rural hospital, most families of patients agreed to participate.
- All families who received the consult were very satisfied with culturally concordant tele-palliative care consult.
- Community has "ownership."



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The first such program in the US.
Elk et al., (2020) Health Equity, Vol. 4.1

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EXAMPLES FROM TABLE 12: (COMMUNITY GUIDELINES) 1. HOW TO ADDRESS THE PATIENT/FAMILY:

WHITE	AFRICAN AMERICAN
Introduce yourself, then ask patient and caregiver.	
Establish Rapport	
NEVER be rude, <i>always</i> be courteous.	
	<ul style="list-style-type: none"> • Do NOT call patient by first name unless invited to do so. • Take AND MAKE time to get to know the patient and family • Learn something about the family, e.g. patient's past occupation/role in church. Repeat it back and then converse about it.

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EXAMPLES FOM TABLE 12: (COMMUNITY GUIDELINES) 3. HOW TO TALK ABOUT PROGNOSIS:

AFRICAN AMERICAN	WHITE
<ul style="list-style-type: none"> Sensitively determine if patient/family want to know about prognosis 	
<ul style="list-style-type: none"> NEVER give bad news to patient if he/she alone. Invite family and pastor 	
<ul style="list-style-type: none"> If they want to know: <ul style="list-style-type: none"> NEVER be blunt NEVER tell patient they're dying NEVER give date and time till death 	2. Honor their decision (i.e. share if want, don't share if don't want)
<ul style="list-style-type: none"> Offer patient/family the opportunity to ask questions. It is physician's responsibility to make sure they are clear. 	3. Be a part of their journey
<ul style="list-style-type: none"> Stress "hope" and "in God's hands" Pray w family if comfortable. 	

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A COMMUNITY-DEVELOPED, CULTURALLY-BASED PC TELE-CONSULT PROGRAM FOR AFRICAN AMERICAN AND WHITE RURAL SOUTHERN ELDERLY WITH LIFE LIMITING ILLNESS
1R01NR017181

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STUDY AIMS

To compare a robust, *culturally-based palliative care (PC) tele-consult program* to usual hospital care.

- a) Primary Aim:** Determine whether a culturally-based PC tele-consult program leads to lower symptom burden in hospitalized AA and W older adults with a life-limiting illness.
- b) Secondary Aim:** Determine whether a culturally-based PC tele-consult program results in higher patient and caregiver quality of life, care satisfaction, and lower caregiver burden at Day 7 post-consultation, and lower resource use (hospital readmission, ER visits) 30-days post-Baseline.
- c) Exploratory Aim:** Explore mediators and moderators of patient symptom and caregiver burden outcomes.

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Knowledge that will change your world.

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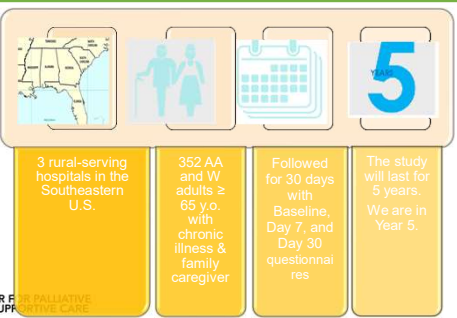
BEFORE STUDY START: COMMUNITY MEMBERS TRAINED THE P.C. PHYSICIANS



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HOW IS THE STUDY CONDUCTED?




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STUDY 2:

- Aim:
- Use CBPR Approach to create training videos by African American community members
- to train clinicians in how to care for older African Americans with serious illness in a culturally sensitive manner.



Step 1: Met with local pastors to get permission and their input

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COMMUNITY DEVELOPED & CREATED VIDEOS

- Community Advisory Board created series of videos on how clinicians who care for older, southern, rural, African Americans with a serious illness on how to care for these patients in a culturally appropriate and respectful manner.
 - “African American Communities Speak to Healthcare Providers”**




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TRAININGS AVAILABLE @ UAB FOR GROUPS

- Education-Trainer collaborator endorsed these videos within training module
- Based on adult learning skills and Transformative Learning Theory (fosters effective behavior change)
- 200 clinicians from around US have been trained.
- High demand for this training, hold it several times a year (3 hours via zoom)



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RESULTS (1) KNOWLEDGE OF AFRICAN AMERICAN (AA) CULTURAL VALUES

	POST N=147	PRE N=168	
Attitudes of southern, AA patients being told diagnosis	3.99 (0.62)	2.90 (0.92)	<0.001
Attitudes of Southern, AA patients being told prognosis	3.96 (0.61)	2.84 (0.90)	<0.001
death & dying	3.88 (0.65)	2.91 (0.88)	<0.001
Belief that religious strengths sustain pt. & family during times of distress	4.28 (0.67)	3.58 (0.93)	<0.001
God decides when person lives or dies	4.23 (0.65)	3.53 (0.93)	<0.001
There is always hope	4.36 (0.62)	3.64 (0.94)	<0.001
Pastor is central to decision-making	4.23 (0.68)	3.33 (0.94)	<0.001
Belief that a miracle can take place & patient can heal	4.24 (0.68)	3.50 (0.94)	<0.001
Context of where my patients were born and raised	3.89 (0.78)	2.85 (0.97)	<0.001
Context of lives of my patients and families including hardships they endured	3.78 (0.80)	3.03 (0.98)	<0.001
Decision-making Style: How decisions re treatment considerations made	3.94 (0.80)	2.85 (0.98)	<0.001
What treatment decisions are made	3.76 (0.81)	2.78 (0.85)	<0.001
Who patient/family wants to be involved in decision-making	4.21 (0.72)	2.96 (0.88)	<0.001
Environmental factors that my patients/family live in	3.62 (0.82)	2.99 (0.91)	<0.001
Degree of family/community/social resources have	3.90 (0.73)	3.05 (0.91)	<0.001
Degree of family resources have access to	3.87 (0.75)	2.90 (0.88)	<0.001
Understanding patient/family has around treatment options	3.78 (0.72)	2.96 (0.85)	<0.001
Community resources pt/family can have to	3.52 (0.83)	2.74 (0.88)	<0.001

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RESULTS (3): IMPLEMENTATION OF COMMUNITY RECOMMENDATIONS @ 3-9 MTHS

	AI*	N
N=194		
Do you have family member(s) present when you discuss diagnosis, prognosis, or goals of care?:		104
Always	35 (33.7%)	
Sometimes	66 (63.5%)	
Not Changed	3 (2.88%)	
Do you emphasize hope when discussing serious news, either opening with a statement of hope or connecting to hope with an "and" rather than a "but"?:		96
Always	50 (52.1%)	
Sometimes	43 (44.8%)	
Not Changed	3 (3.12%)	
Do you proactively plan for clergy involvement in these conversations?:		94
Always	17 (18.1%)	
Sometimes	55 (58.5%)	
Not Changed	22 (23.4%)	
Do you assure equal care always by making an explicit statement that you are providing the best care?:		97
Always	63 (64.9%)	
Sometimes	24 (24.7%)	
Not Changed	10 (10.3%)	

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R01 SUBMITTED

African American (AA) Communities Speak:
Partnering with AAs in the North and South to
Train P.C. Clinicians to Address Interpersonal & Systemic Racism
and
Provide Culturally Aligned Care

[Score: 2, percentile: 4]

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COMMUNITY BASED PARTICIPATORY RESEARCH INTENSIVE TRAINING

COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR) IMMERSION TRAINING: A Social Justice Approach

July 17-20, 2023
Every Day 10:00am - 4:30pm
VIRTUAL TRAINING

REGISTER HERE

WHAT WILL APPLICANTS GAIN INSIGHT INTO?

- Principles, methodologies, and equitable relationships across disciplinary understandings
- Research approaches relevant to CBPR and other research approaches
- Social justice aspects of CBPR
- How to partner with communities equitably and respectfully
- How to establish and operationalize trust
- The history and current role of Community Advisory Groups throughout the life cycle process
- The principles and practice of team science

WHO IS THIS INTENSIVE TRAINING FOR?

This training is designed for researchers, clinicians, educators, and/or healthcare administrators who are committed to health equity.

APPLICATION PROCESS

- Registration deadline is May 15, 2023
- Only those who register will be invited to the course
- \$1,000 stipend fee
- Limit to 50 participants

Training will give access to information regarding future training and networking opportunities.

EMERGENCY CREDENTIALS will be allowed.

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CREATING AND IMPLEMENTING CULTURALLY-BASED SOCIAL JUSTICE-FOCUSED PROGRAMS IN 4 STEPS:

1. Listen to the voices of the community
Researchers, Clinicians
2. Build programs based on what the community values
Researchers, Program Admin
3. Train clinicians in this culturally-based program
Educators
4. Implement this program in healthcare settings
Clinicians, Educators, Admin.

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Elk & Gazaway, 2021, Journal of Law & Medicine, 49, 222-230

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I'M A CLINICIAN, WHAT CAN I DO? STEP 1

Journal of Palliative Medicine
Volume 16, Number 2, 2011
© May 2011 Lippincott Williams & Wilkins
DOI: 10.1097/JPM.0b013e318210200a

Notes from the Editor

The First Step Is Recognizing, Acknowledging, and Respecting the Inequity, Disrespect, and Disregard Our African American Patients Have Experienced

Ronit Elk, PhD, Special Issue Guest Editor

"It is our duty as clinicians to do our best to recognize, acknowledge, and respect the profound effects of past and present racism." — recognizing that "African American patients may have had experiences of being treated with inequality, disrespect, and disregard," and recognizing that there are "many disparities that can be recognized and addressed that have not been done so." It was to be expected.

We recognize that none of us can erase the past, so here we do "our best" forward. Dr. Pagan's paper recommends three opportunities by which we can improve care for African American patients who are approaching the end of life: the first step is our recognition, acknowledgment, and respect of the inequities, mistreatment, and racism that our African American patients may have suffered and often continue to suffer. To do this well, we must become aware of, and directly work on, our own internal biases. Most of us are unaware of our own biases, and people often do not realize we have an issue. We must be people of color and the conversations with our African American colleagues, friends, and patients to create the culture we seek to achieve. — Ronit Elk, PhD

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WHAT CAN I DO? STEP 2: ABCDE

<h4>Attitudes</h4> <p>What are the patient and family members' attitudes toward diagnosis?</p> <p>Educate yourself about attitudes common to ethnic groups; understand symbolic meaning</p>	<h4>Beliefs</h4> <p>What are the religious and spiritual beliefs?</p> <p>Acknowledge spirituality and religion and ask what they want you to know about it.</p>	<h4>Context</h4> <p>Gain some understanding of their cultural context such as background, experiences, etc...</p> <p>Ask how these experiences will impact their care</p>	<h4>Decision Making</h4> <p>Determine how the patient makes decisions</p> <p>Ask if there is deferral of autonomy to the family/pastor? Etc.</p>	<h4>Environment</h4> <p>What resources are available to the patient and family?</p> <p>Determine if there are missing resources & identify agencies that can help provide these</p>
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Kagawa-Singer, M. & Blackwell, L.J. JAMA. 2001 Dec 19;286(23):2993-3001. Negotiating cross-cultural issues at the end of life: "You got to go where he lives".

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WANT TO FIND OUT MORE ABOUT THE TRAININGS OR CONDUCTING YOUR OWN RESEARCH?

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