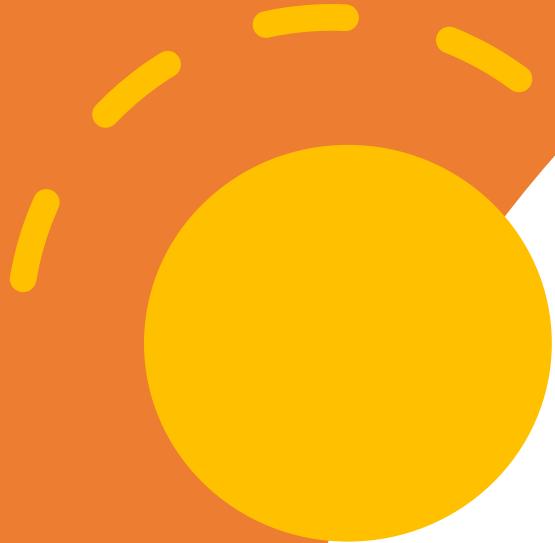




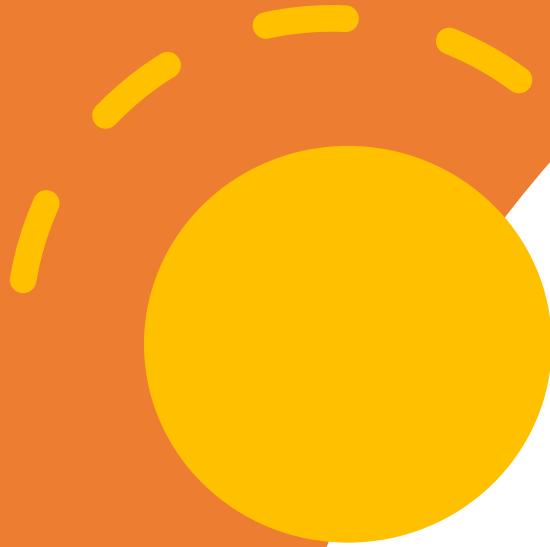
How to Support African American Patients and Families at End of Life

Gloria Thomas Anderson, Ph.D., LMSW

Objectives:



- 1) To examine the unique historical, cultural, and spiritual values that can influence African-American end-of-life decision-making.
- 2) To gain an understanding about collectivism and individualism as it relates to communication styles and some of the barriers that can hinder culturally responsive care.
- 3) To consider best practice behaviors using the “Be the Change” model and social work values for culture care service delivery.



Note:

Broad Diversity in the African American Population

Intragroup Diversity

No two people exactly alike, even in same ethnic group

Objective 1)

- To examine the unique historical, cultural, and spiritual values that can influence African-American end-of-life decision-making.

Historical Mistrust in Healthcare



- Research shows difference in medical care between black people and white people
- Less use of cardiac procedures
- Reduced access to renal transplants
- Fewer surgeries for lung cancer

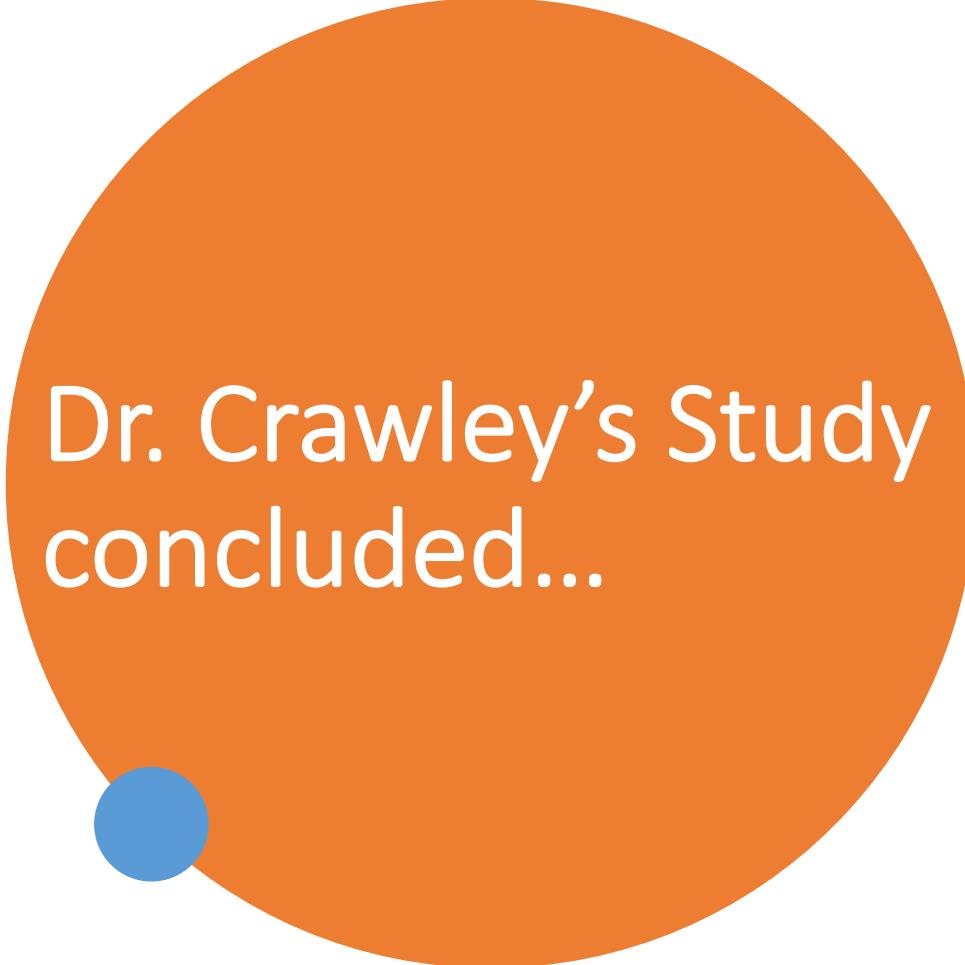
(Wicher, 2012; Rhodes, 2015)



The Tuskegee Experiment



- 300 Black men with syphilis
- Not given cure
- Well-known fact in Black community



Dr. Crawley's Study concluded...

- Clinicians acting on racial biases
- Clinicians making decisions for patients without their input
- Patients not given "a say" in their own end-of-life care

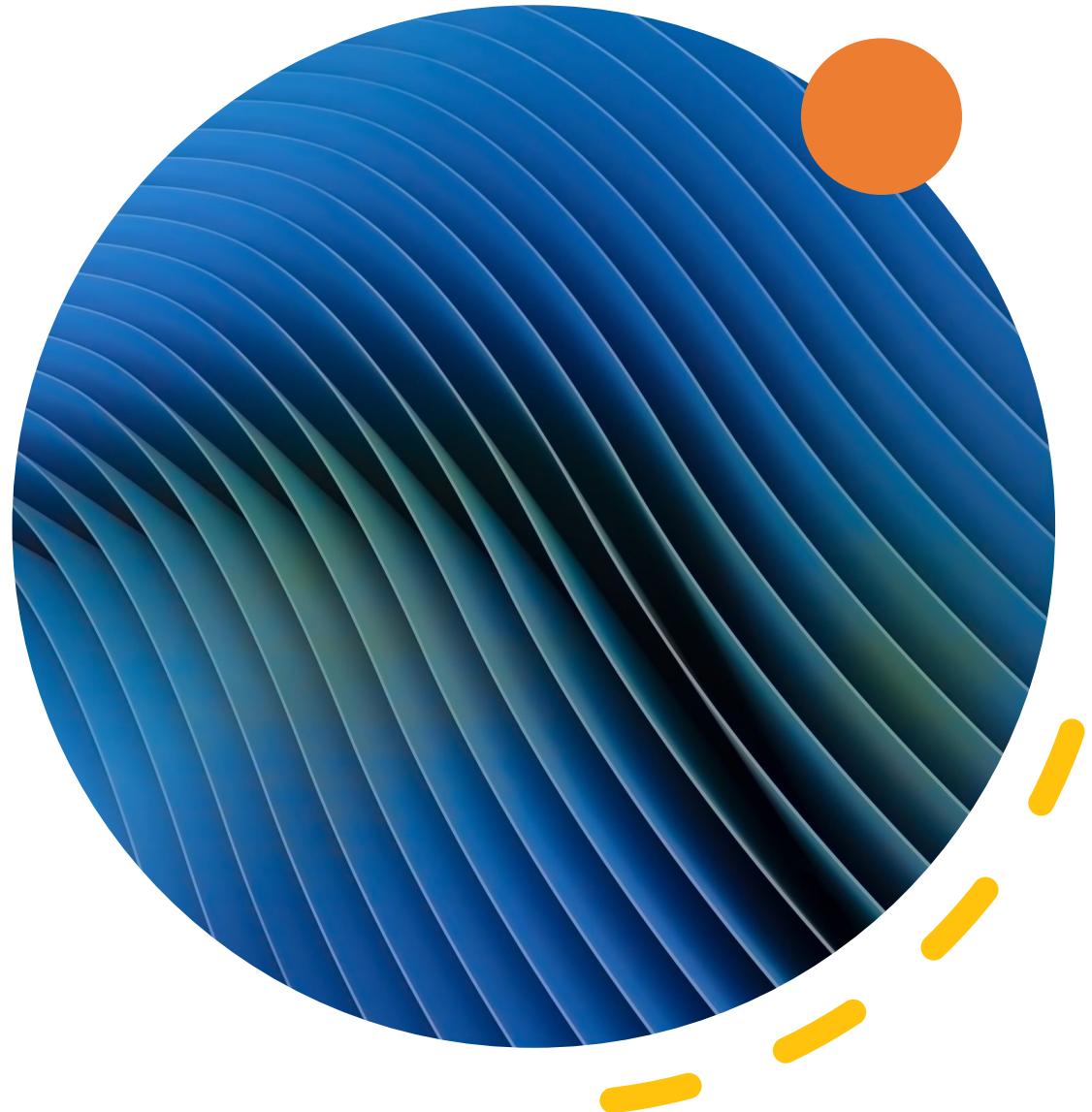
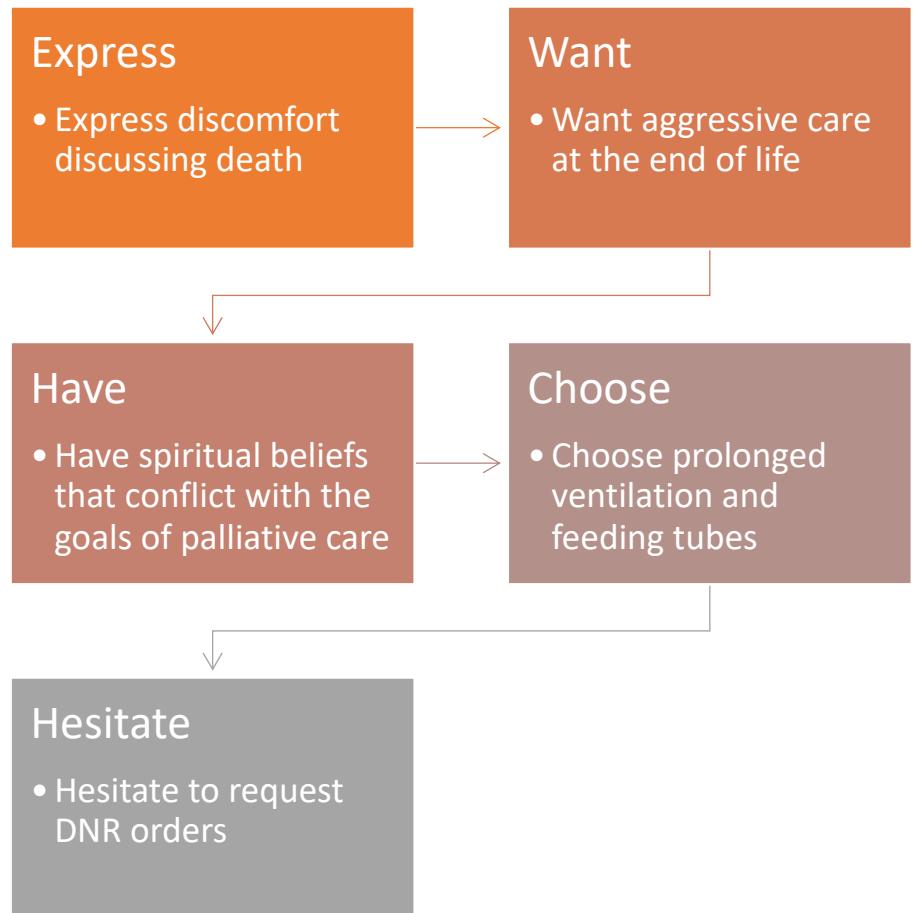


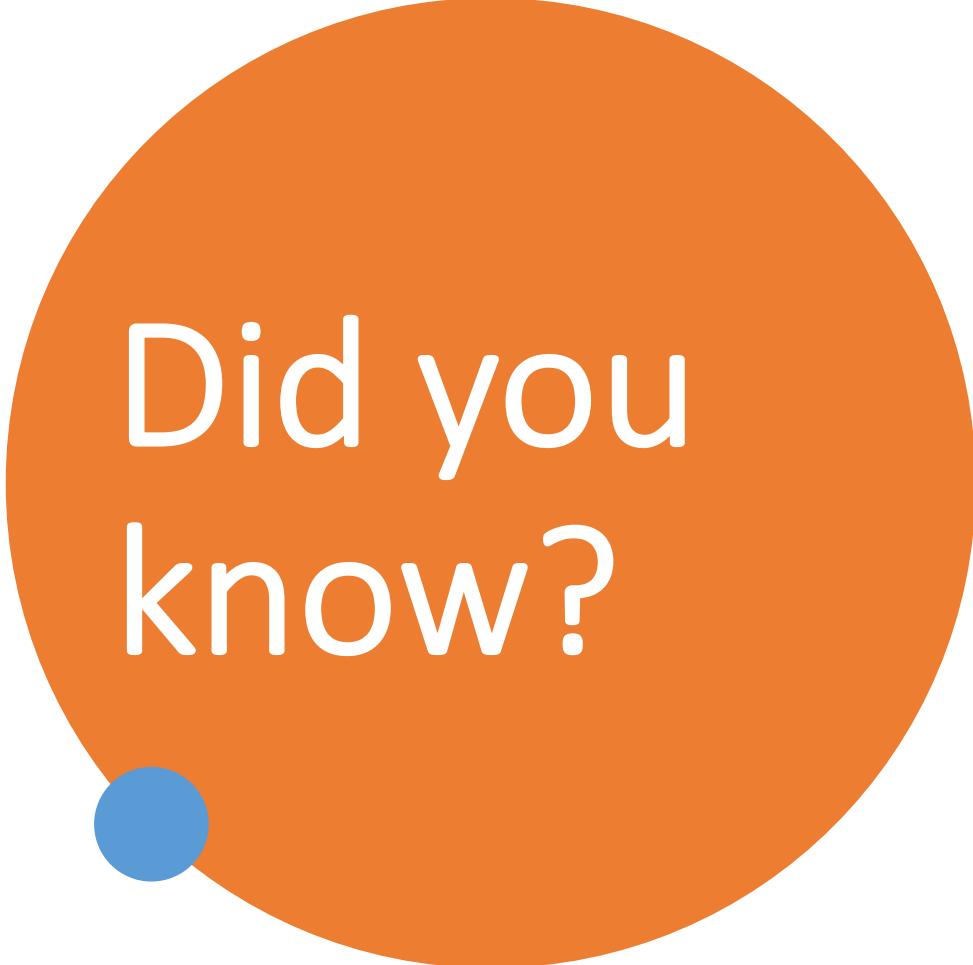
Trust is something medical providers must *earn*, not something patients must give.

(Elbaum, 2020)

Historical Values

Studies show African American people are more likely to...





Did you
know?



56% of African Americans
express mistrust in the medical
system due to a history of
oppression and unethical
practices.

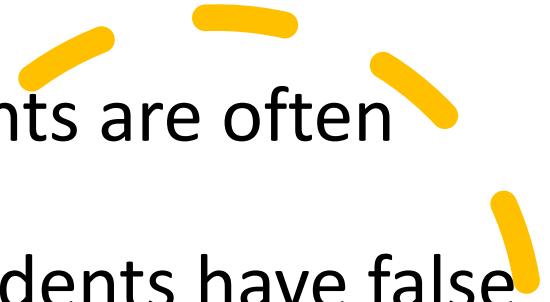
(Commonwealth Fund, 2021)



According to
Commonwealth
Fund (2021)...

- African American patients are often undertreated for pain.
- One-half of medical students have false beliefs about biological differences between African American and White American patients/
- Myth that Black people have higher tolerance for pain than White people.

(Commonwealth Fund, 2021)



Some Traditional Cultural Values

Family—Children, Extended Family,
Fictive Kin

Unity—Collective Identity, Groups

Heritage—Belief Systems, Traditions

Some Southern Generational and Family Values



Determining how they make sense of life and death in approaching end-of-life decision-making (Bullock, 2011)

- Sacrificing one's own needs
- Family directed care
- Relief from physical and financial stress (Born, et.al, 2004)
- Focusing on “life” rather than “death”
- Relying on their spirituality and faith, including prayer

Is Religion the same as Spirituality?

Religion—a particular set of institutionalized belief systems and standards that provide direction and instruction for one's life.

vs

Spirituality—a personal expression and/or connectedness (relationship with) something or someone greater than the self that gives meaning and purpose to one's life.

Cultural Influence of Spirituality, Religion and Faith



- West African backgrounds
- Slavery
- Loss of heritage



According to
a recent
study...

Difficult and important end-of-life decision-making in the African American population is greatly influenced by one's faith in God and God's control over life.

(Collins et al, 2021).

Religion, Spirituality and the Black Church



- 85% of African Americans describe themselves as “born again” or evangelical Protestants. (Pew Research Center, 2020)
- Many African Americans return to their religious/cultural beliefs at the end of life. (Ersek, Kawaga-Singer, Barnes, Blackhall, & Koenig, 1998)
- The Black Church plays a key role in many African Americans’ everyday lives.

Some Recurrent Themes in African American Spiritual Beliefs are...



- A source of comfort, coping and support
- Prayer as an effective way to influence healing (Pew Research Center, 2021)
- God is responsible for physical and spiritual healing
- The doctor is God's instrument (Johnson, Elbert-Avila & Tulsky, 2005)
- Faith in God and belief in life after death (Collins, et al, 2021)

The Significance of Prayer...



Prayer as an effective way to influence healing...

- 78% of Black Americans believe prayer can heal physical illness
- 1/3 of Black Americans say prayers to ancestors can protect them
- 8 in 10 pray at least twice a month
- 63% report they pray daily
- 72% of Black Protestants are likely to rely on prayer when making major decisions

(Pew Research Center, 2021)

Objective 2)

- To gain an understanding about collectivism and individualism as it relates to communication styles and some of the barriers that can hinder culturally responsive care.

Understanding Differing Communication Styles

African American Cultural Communication Style

Collectivism—The belief that one's identity is in large part a function of one's membership and role in a group;

Interdependence and harmony of group members are valued.

Western European Cultural Communication Style

Individualism—The belief that the needs of the individual should be satisfied before those of the group;

Independence and self-reliance are valued.

Understanding Differing Communication Styles

African American Cultural Communication Style

Indirect—Understated or implied; the message may not be clearly spoken but inferred; Relies less on words.

High Context—Pay attention to what is not being said in the conversation. Non-verbal cues may indicate what is really being said.

Western European Cultural Communication Style

Direct—Stated or clearly spoken message; to say exactly, literal; relies more on words; getting or giving information is the goal of direct communication

Low Context—Pay attention to what is being said in the conversation. Verbal expression spells out clearly what is being said.

Some Barriers to Culturally Responsive End-of-Life Care

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency missteps

True Case Study:
(Situation #1 of 3)
Elderly, black
woman brought to
the ER;
afraid of hospitals;
knew about
Tuskegee
experiment;
experienced racial
discrimination;

*Which two barriers
best identify this
situation?*

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency missteps

True Case Study:
(Situation #1 of 3)
Elderly, black
woman brought to
the ER;
afraid of hospitals;
knew about
Tuskegee
experiment;
experienced racial
discrimination;

*Which two barriers
best identify this
situation?*

ANSWER

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency Missteps

True Case Study:
(Situation #2 of 3)
Elderly, black
woman
in ER room
white male nurse
calls her “Sweety”
insults and angers
her

*Which two barriers
best identify this
situation?*

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency missteps

True Case Study:
(Situation #2 of 3)
Elderly, black
woman
in ER room
white male nurse
calls her “Sweety”
insults and angers
her

*Which two barriers
best identify this
situation?*

ANSWER

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency missteps

True Case Study:

(Situation #3 of 3)

Elderly, black woman moved to hospital bed
white, female nurse asks about advance directive; no explanation
patient misunderstood; gave unexpected reaction;

Which two barriers best identify this situation?

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency missteps

True Case Study:
(Situation #3 of 3)
Elderly, black woman
moved to hospital bed
white, female nurse
asks about advance
directive; no
explanation
patient
misunderstood; gave
unexpected reaction;

*Which two barriers
best identify this
situation?*

ANSWER

- 1) Racial disparity in health care
- 2) Mistrust of doctors and proposed treatment options
- 3) Miscommunication & misconceptions
- 4) Cultural Competency missteps

Self-Reflection Checklist for Supportive End-of-Life Care

- Am I knowledgeable about historical medical mistrust?
- Am I aware of cultural beliefs, values and traditions?
- Am I establishing a trusting relationship?
- Am I communicating honestly and respectfully? *
- Am I learning about the patient as an individual?
- Have I gained an understanding about the cultural communication styles and potential barriers to supportive care delivery?
- Am I integrating religious and cultural beliefs into the care plan as it pertains to the client's goals of care preferences?

(Bullock, 2011; Rhodes et al, 2017)

Objective 3)

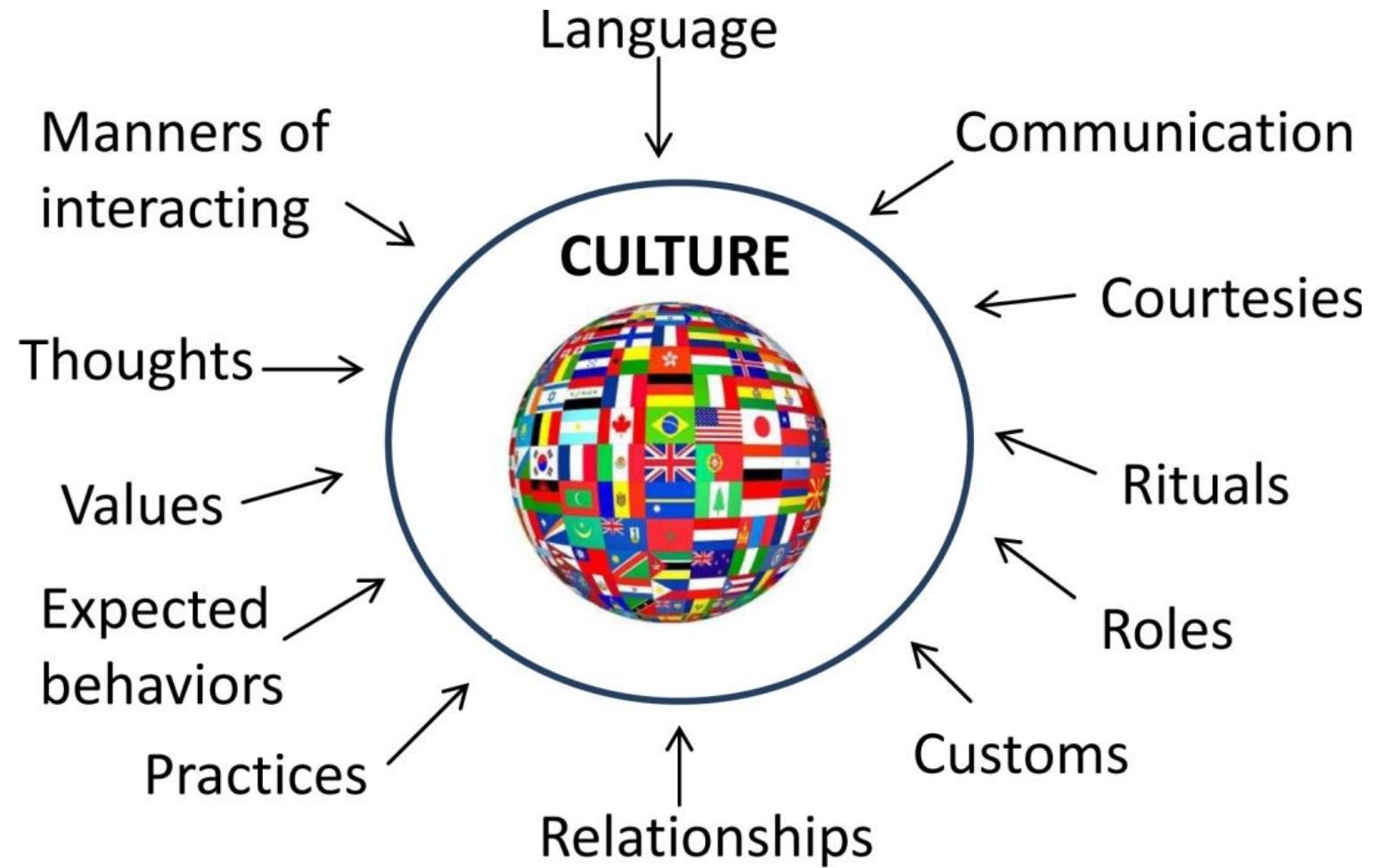
- To consider best practice behaviors using the “Be the Change” model and social work values for culture care service delivery.

Culture Care is...

... care that is meaningful, desired by, and congruent with the values, beliefs, and practices of the patient.

(Collins et al, 2021).

The Role of Culture



Be the change...



Mahatma Ghandi

“You must be the change you
wish to see in the world.”

BE THE CHANGE Model

Social Work Core Values as Best Practices Action Steps

Service.

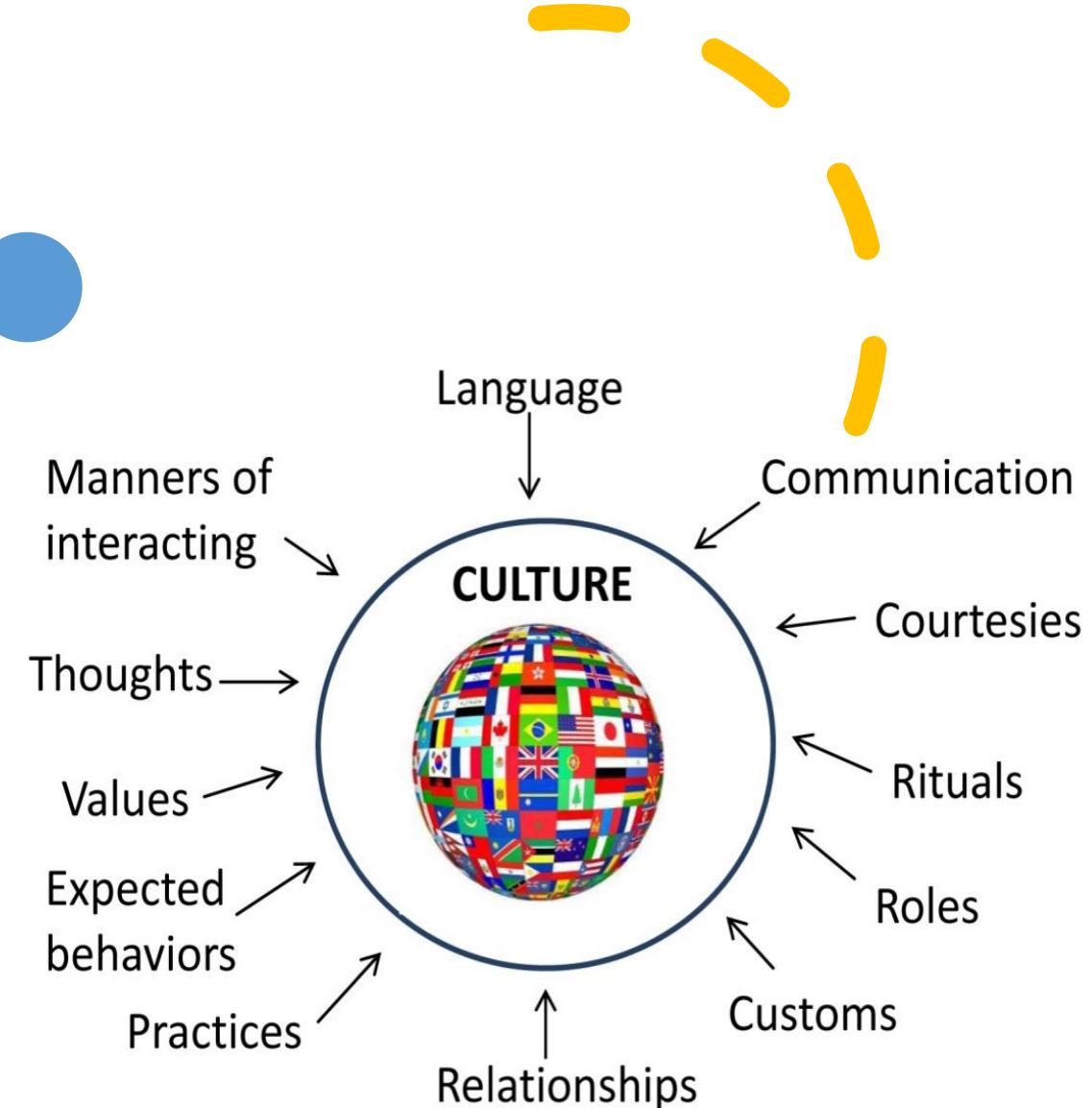
Social justice.

Dignity and worth of the person.

Importance of human relationships.

Integrity.

Competence.



BE THE CHANGE Model

Social Work Core Values as Best Practices Action Steps

Step 1→ **BE** a politically motivated advocate in **Service** to vulnerable people.

Step 2→ **BE** an agent of **Social Justice** by using your voice and position to promote equitable, institutional change.

Step 3→ **BE** willing to “listen”, not just to “hear”; open to “learning”, not just to “knowing” for the **Dignity and Worth of the Person** begins with his/her own stories, struggles and strengths and has value to them.

BE THE CHANGE Model

Social Work Core Values as Best Practices Action Steps

Step 4→ **BE** empathic to diverse others, reflecting the Importance of **Human Relationships**.

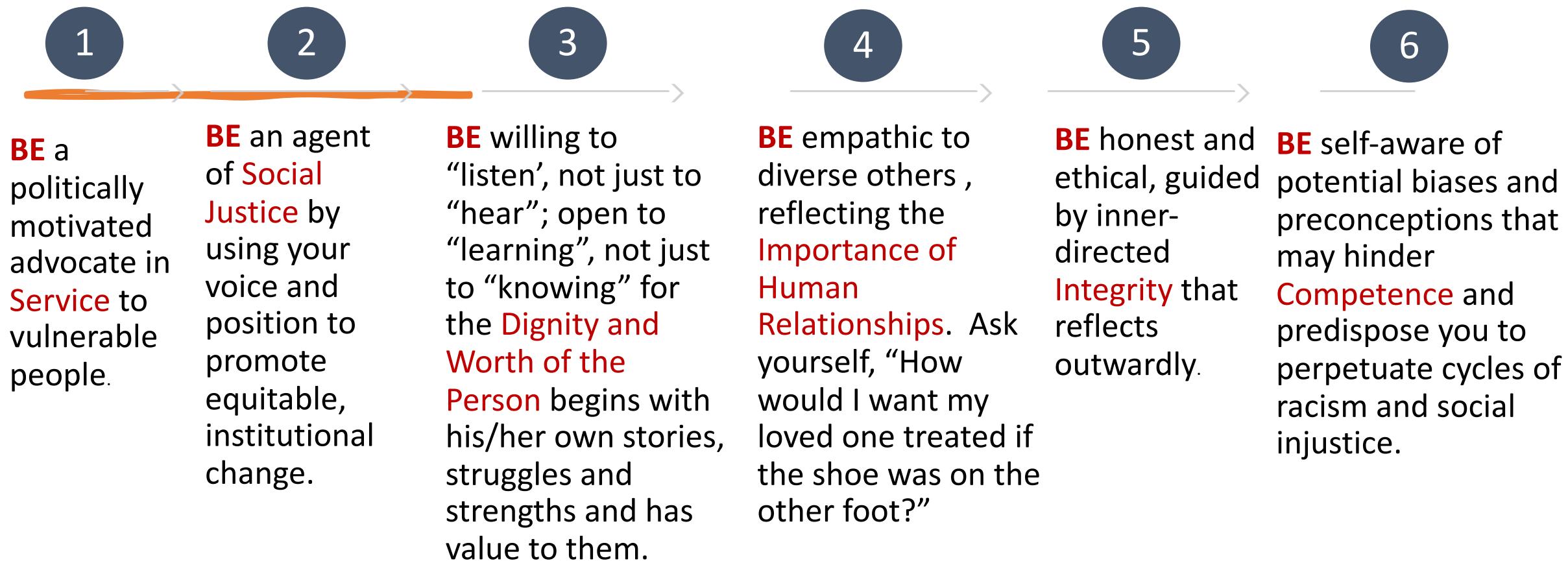
Step 5→**BE** honest and ethical, guided by inner-directed **Integrity** that reflects outwardly.

Step 6→ **BE** self-aware of potential biases and preconceptions that may hinder **Competence**.

Self-Reflection Question:
“How does this model align with my own
best practice behaviors”?

BE THE CHANGE Model

Social Work Core Values as Best Practices Action Steps





This moment marks the beginning of a new opportunity to make a positive difference in my world of care. /

—Dr. Gloria Thomas Anderson

Thank You
for
Attending!

Presenter Contact Information:



Gloria Thomas Anderson, Ph.D., LMSW



hello@hearttones.com

References

- Brandon, D. T., Isaac, L. A., & LaVeist, T. A. (2005, July). The legacy of Tuskegee and trust in medical care: Is Tuskegee responsible for race differences in mistrust of medical care? *Journal of the National Medical Association*, 97(7), 951. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2569322/pdf/jnma00188-0013.pdf>
- Bullock, K. (2011, March 3). The Influence of Culture on End-of-Life Decision Making. *Journal of Social Work in End-Of-Life & Palliative Care*, 7(1), 83–98. <https://doi.org/10.1080/15524256.2011.548048>
- Collins, J., Zoucha, R., Lockhart, J.S., and Mixer, S.J. (2021). Cultural aspects of end-of-life advance care planning for African Americans: An ethnonursing study. *Journal of Transcultural Nursing*; 32(5) 558–566. DOI: 10.1177/1043659620960788
- Collins, J., Zoucha, R., Lockhart, J.S., and Mixer, S.J. (2018). Cultural aspects of end-f-life care planning for African Americans: An integrative review of literature *Journal of Transcultural Nursing*, 29(6). <https://doi.org/10.1177/1043659617753042>
- Elbaum, A. (2020, June 29). Black Lives in a Pandemic: Implications of Systemic Injustice for End-of-Life Care. *Hastings Center Report*, 50(3), 58–60. <https://doi.org/10.1002/hast.1135>
- Institute of Medicine (IOM) (2002). *Unequal Treatment: Understanding Racial and Ethnic Disparities in Health Care*. Retrieved May 20, 2006, from <http://www.nap.edu/catalog/10260.html>
- Johnson, K.S., Elbert-Avila, K.I., and Tulsky, J.A. (2005). The Influence of Spiritual Beliefs and Practices on the Treatment Preferences of African Americans: A Review of the Literature. [Electronic version]. *The Journal of American Geriatrics Society*, 53(4), 711-719.
- Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2008, October 1). What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care? *Journal of the American Geriatrics Society*, 56(10), 1953–1958. <https://doi.org/10.1111/j.1532-5415.2008.01919.x>
- Meghani, S. H., Byun, E., & Gallagher, R. M. (2012). Time to take stock: a meta-analysis and systematic review of analgesic treatment disparities for pain in the United States. *Pain medicine (Malden, Mass.)*, 13(2), 150–174. <https://doi.org/10.1111/j.1526-4637.2011.01310.x>
- Pew Research Center for the People & the Press; Survey Reports The 2004 Political Landscape; Evenly Divided and Increasingly Polarized; Released: November 5, 2003 Part 8: Religion in American Life [Electronic version]. Retrieved May 20, 2006 from <http://peoplepress.org/reports/print.php?PageID=757>
- Pew Research Center (2021). New findings about faith among black americans. Retrieved February 25, 2022 from <https://www.pewresearch.org/fact-tank/2021/02/16/10-new-findings-about-faith-among-black-americans/>
- Rhodes, R. L., Batchelor, K., Lee, S. C., & Halm, E. A. (2015, March 1). Barriers to End-of-Life Care for African Americans From the Providers' Perspective. *American Journal of Hospice and Palliative Medicine®*, 32(2), 137–143. <https://doi.org/10.1177/1049909113507127>
- Rhodes, R.L., Elwood, B., Lee, S.C., Tiro, J.A., Halm, E.A., and Skinner, C.S. (2017). The desires of their hearts: The multidisciplinary perspectives of African Americans on end-of-life care in the African American community. *American Journal of Hospice & Palliative Medicine*; 34(6) 510-517. <https://doi.org/10.1177/1049909116631776>
- Wicher, C.P. and Meeker, M.A. (2012) What influences African American end-of-life preferences? *J Health Care Poor Underserved*. 23(1):28–58.