



# 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...

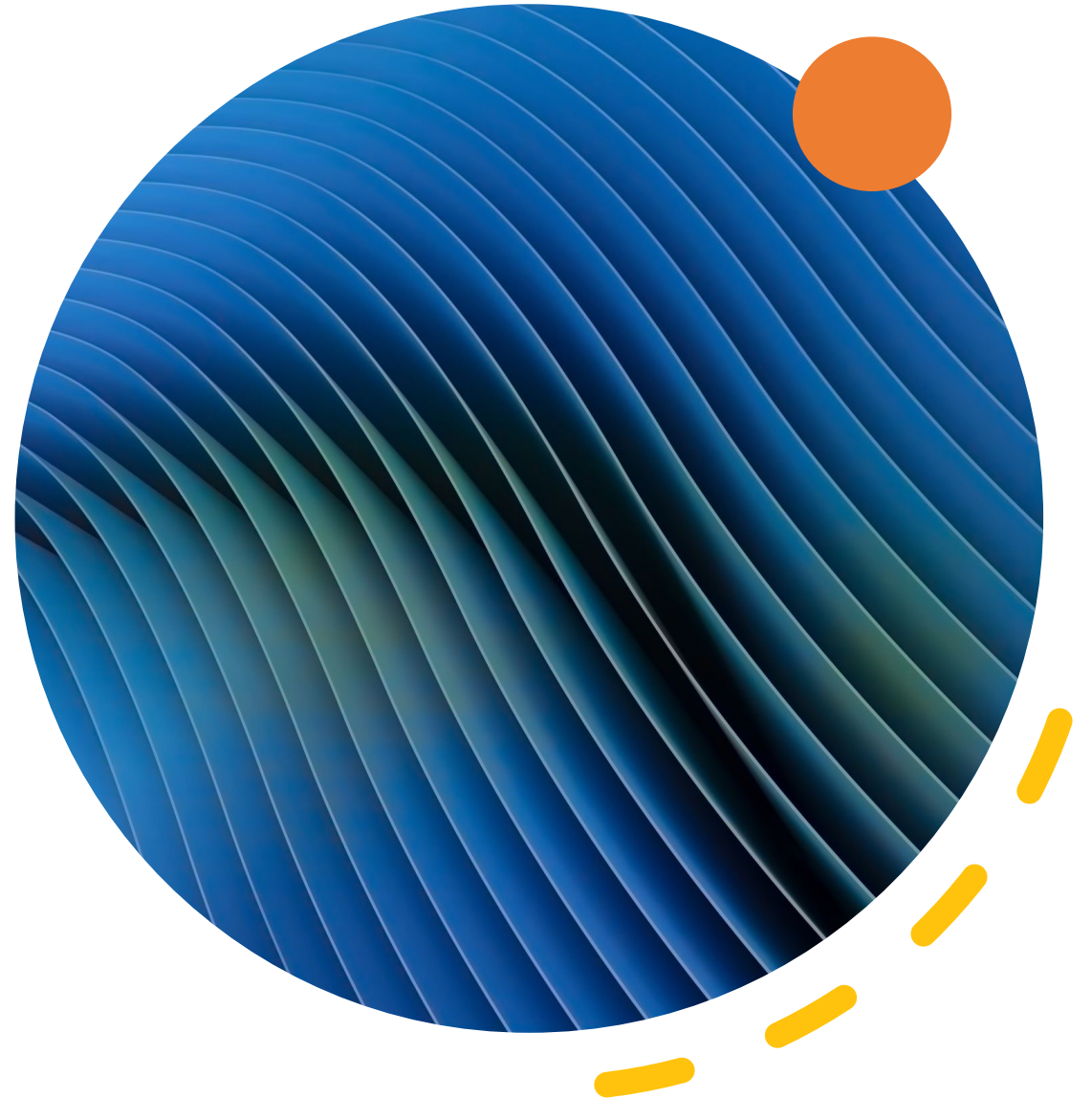
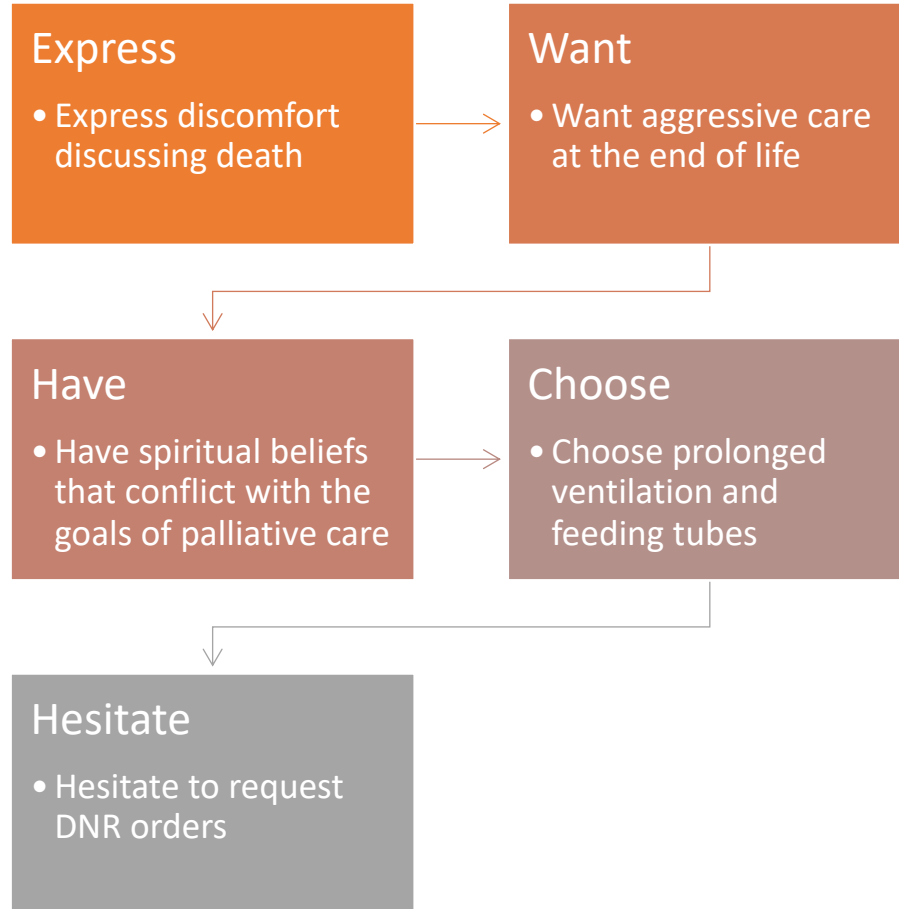
- Clinicians acting on racial biases
- Clinicians making decisions for patients without their input
- Patients not given "a say" in their own end-of-life care

**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

An orange rounded rectangular box containing the text 'Family—Children, Extended Family, Fictive Kin' in white. A light orange arrow points downwards from the bottom right corner of this box towards the middle box.

**Unity**—Collective Identity, Groups

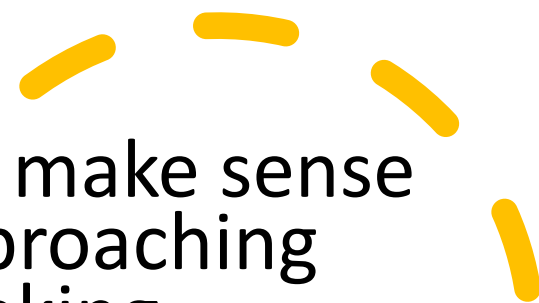
A gray rounded rectangular box containing the text 'Unity—Collective Identity, Groups' in white. A light gray arrow points downwards from the bottom right corner of this box towards the bottom box.

**Heritage**—Belief Systems, Traditions

A yellow rounded rectangular box containing the text 'Heritage—Belief Systems, Traditions' in white.



## 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

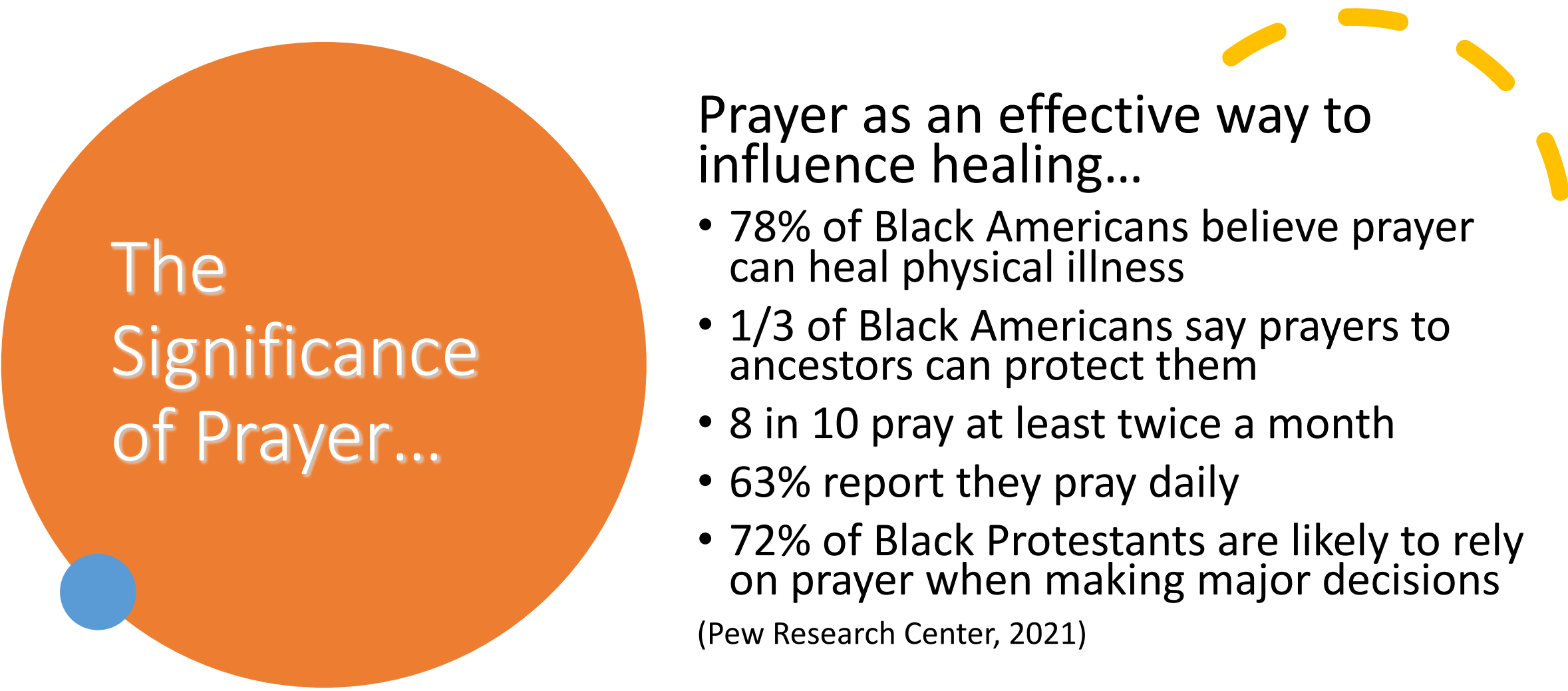
- 85% of African Americans describe themselves as “born again” or evangelical Protestants. (Pew Research Center, 2020)
- Many African Americans return to their religious/cultural beliefs at the end of life. (Ersek, Kawaga-Singer, Barnes, Blackhall, & Koenig, 1998)
- The Black Church plays a key role 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 & Tulskey, 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	Western European Cultural Communication Style
<p><b>Collectivism</b>—The belief that one's identity is in large part a function of one's membership and role in a group;</p> <p><b>Interdependence and harmony of group members are valued.</b></p>	<p><b>Individualism</b>—The belief that the needs of the individual should be satisfied before those of the group;</p> <p><b>Independence and self-reliance are valued.</b></p>

# 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
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# ANSWER

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

*Which two barriers  
best identify this  
situation?*

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## 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  
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- 1) Racial disparity in health care
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# 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.

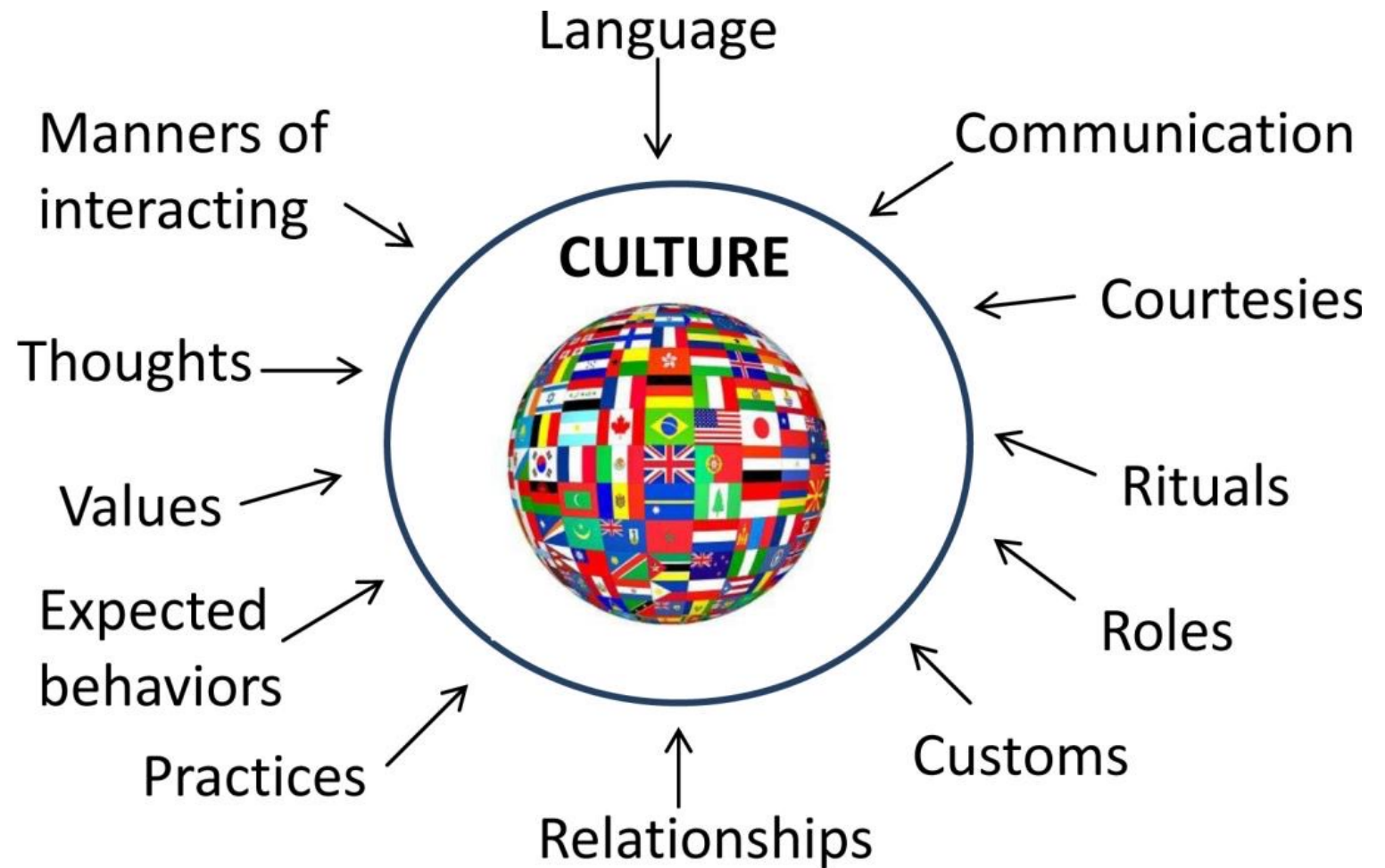
# Culture Care is...

... 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

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Be the change...



Mahatma Gandhi

“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.

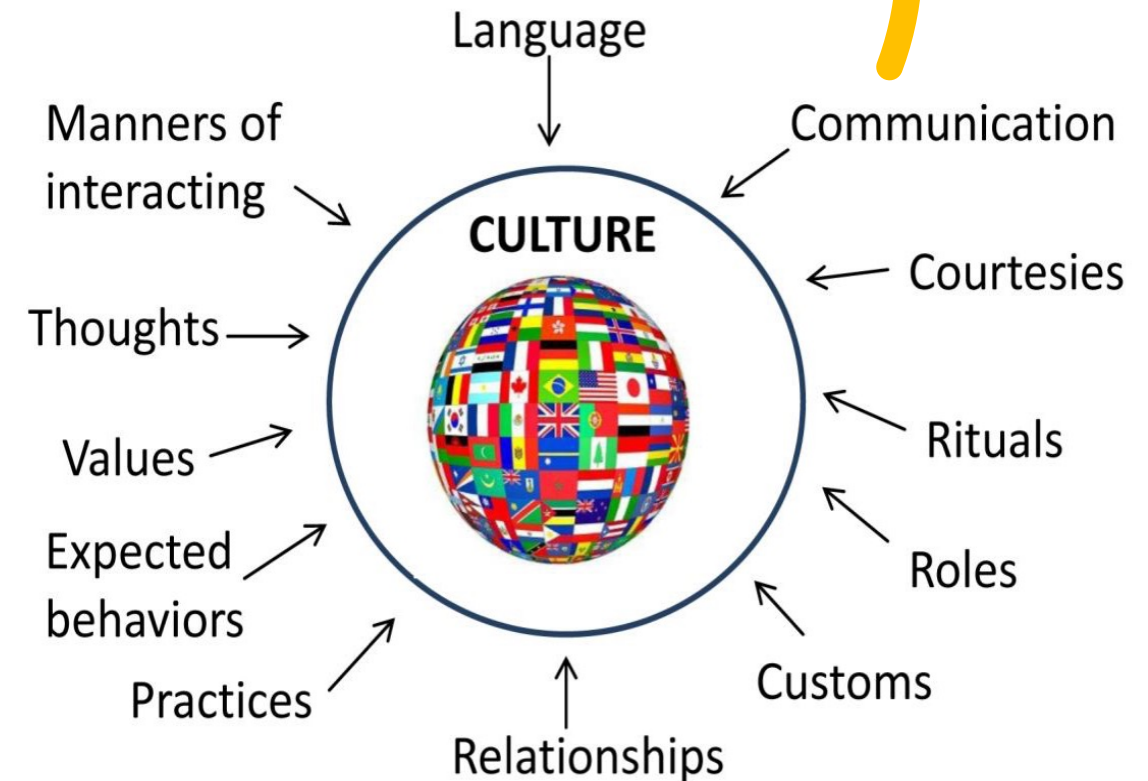
Social justice.

Dignity and worth of the person.

Importance of human relationships.

Integrity.

Competence.



# BE THE CHANGE Model

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## *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

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## *Social Work Core Values as Best Practices Action Steps*

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

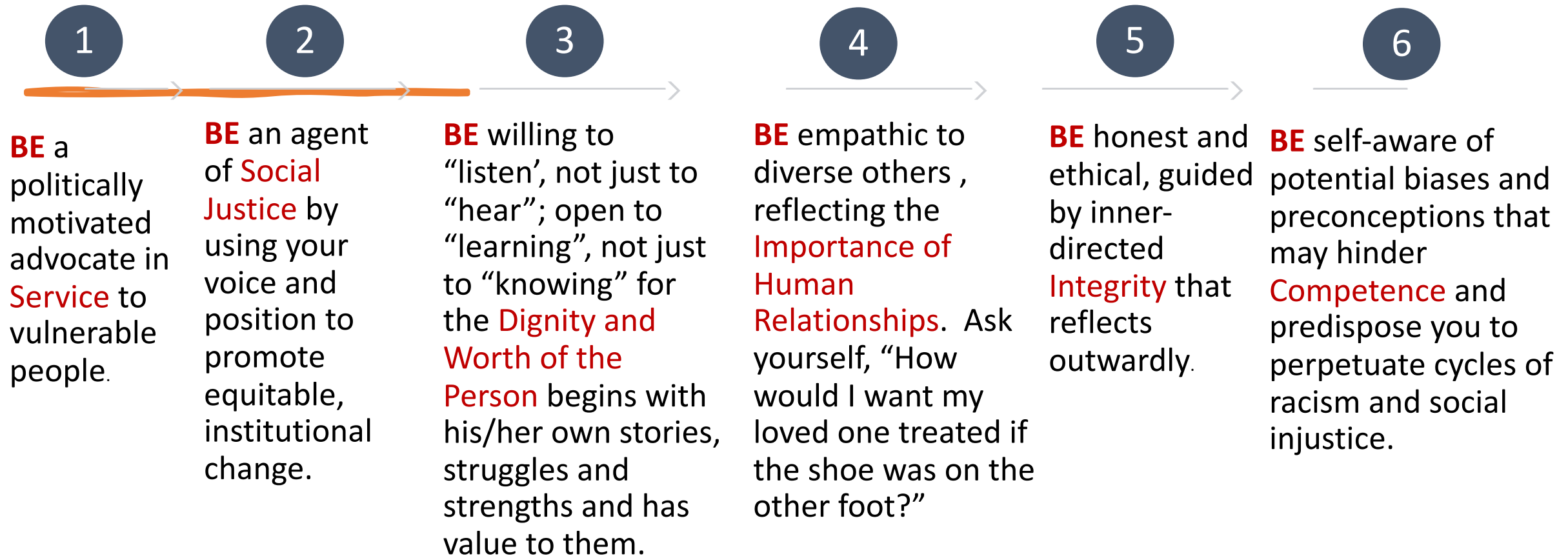
Step 5→ **BE** honest and ethical, guided by inner-directed **Integrity** that reflects outwardly.


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!

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# 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 ethn nursing 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-of-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 Tulskey, 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., & Tulskey, 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://people-press.org/reports/print.php3?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.