What Y’all Gon’ Do With Me?

The African-American Spiritual and Ethical Guide to End of Life Care

By Gloria Thomas Anderson, MSW

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Purpose

- To provide a consumer friendly guide on end of life issues for African-American population.

- To address the unique cultural, historical and spiritual values in the decision-making process from a strengths perspective of self empowerment.
Purpose - continued

- To increase the participation of African-Americans in the decision-making process of End of Life care.

- To offer a proactive tool that can facilitate and educate this population on important End of Life issues.
Why This Approach?

- Racial disparity in health care (Institute of Medicine, 2002)
- Mistrust of doctors and proposed treatment options
- Miscommunication
- Cultural competency concerns
Why the Historical Mistrust in Healthcare?

- Racism in medicine has always existed and is deeply embedded in institutions, policies and personal mindsets.

  - The Tuskegee syphilis study (Chadwick, 1997)

Barriers to Appropriate and Equitable Health Care and Everyday of Life

- Biases
- Prejudice
- Stereotyping
- Discrimination
- Fear
- Ignorance
- Deception
Isn’t It Time To Advocate For Real Change?

“We must discern not only the poors’ lives, their living conditions, and social connections, but their mistrust of the health care system. We must learn about their cultural, spiritual and religious values. And we must come to appreciate how social, cultural, ethnic and racial experience holds sway over their understanding and response to illness, suffering, dying, and death.”

- David Wendell Moller, Ph.D.
  Director of Sirridge Office of Medical Humanities, School of Medicine, UMKC
Legislative, Policy and Organizational Efforts

- Patient Self Determination Act of 1991
- Healthy People 2010 Agenda
- Initiative to Improve Palliative and End-of-Life Care in the African-American Community (Crawley, Payne, Bolden, Washington, & Williams, 2000)
- The National Medical Association (NMA)
- Institute of Medicine (IOM)
- Pew Research Center (www.people-press.org)
- Commission on Health Disparities and the Impact of Racism on African-American Health Status

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Social and Economic Factors Affect African-American EOL Decisions

1865-1872
1965-1975
(Hood, 2001)

Engrained Institutionalized Racism

The imbalance remains…

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Historical Perspective-Spirituality

- West African backgrounds
- Slavery
- A Spiritual People
- The Church

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Religion vs. Spirituality

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

- Spirituality—a personal expression and/or connectedness with something or someone greater than one’s self that gives meaning and purpose to one’s life.
50% of African Americans say they are “born again” or evangelical Protestants

Religion and spiritual beliefs have been attributed to influencing the treatment preferences of African Americans in the face of illness

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Recurrent Themes in African American Spiritual Beliefs

- A source of comfort, coping and support
- An effective way to influence healing
- God is responsible for physical and spiritual healing
- The doctor is God’s instrument

(Johnson, Elbert-Avila & Tulsky, 2005)
Universal Spiritual Values—
Issues of the Spirit

- Why me?
- What will happen to me?
- What has my life meant?
Spirituality- A Sustaining Force

- 63% of people believed it is good for doctors to talk to patients about their **spiritual** beliefs. (Last Acts Committee, 2002)

- Many African-Americans resort back to their religious and cultural beliefs at the end of life. (Ersek, Kawaga-Singer, Barnes, Blackhall, & Koenig, 1998)
Some African-American Traditional Southern-Based Cultural Values:

- Hard to label/categorize
- High value on friends and non-family relationships
- Family centered approach (“village” concept)
- Family heritage, belief system and traditions
Some Southern African-American Generational and Family Values

- Sacrificing one’s own needs (Born, et.al, 2004)
- Family directed care
- Relying on their spirituality and faith
- Having someone to listen and care
- Relief from physical and financial stress
- Focusing on “life” rather than “death” (Blackhall, Frank, & Murphy, 1999)
The End of Life Guide and Ethics

- To illustrate respectfulness and dignity to the patient’s autonomy
- To include the critical conflicting moral and legal mandates
- To provide pertinent information and resources that could benefit the African American population
Have you gotten your house in order?

14 Important End of Life Issues You Want and Need To Know About
The African-American Spiritual and Ethical Guide to End of Life Care

- Taking Control of Your Life and Health
- Gettin’ Your House in Order
- More to Life than Being “Alive”
The African-American Spiritual and Ethical Guide to End of Life Care

- The “F” Factor—Family, Friends and Foe
- The Healing Balm of Forgiveness
- Coping and Hoping—A Spiritual Journey
- What’s All This “End of Life” Stuff About?

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- Advance Directive Choices
- Planning for Emergency Situations, Even For People Who Are Not Terminally Ill
- 5 Important Things To Do

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- Embracing Life
- Puttin’ On My Traveling Shoes
- Comforting Words
- Your Legacy...Your Life.
Your Legacy—Your Life

What’s really important at the end of life?

- Building memories
- Leaving a legacy to be remembered by
Tomorrow’s Hope

Hope is the substance of renewal and strength that gives courage to go on.
Hope is the quiet stillness comforting the soul as a broken heart mourns.
Hope is the light that merges with faith, a new beginning to be born.
Such is the precious gift of tomorrow’s hope—a treasured jewel to adorn.

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Community Building/Collaboration

- Be a key “End of Life Care Provider” in your community:
  - Churches/Clergy
  - Social Services Organization
  - Health Care Organizations
  - Hospice and Palliative Care Organizations
  - Political Representatives
  - Families and Friends
What Can You Do To Help Educate the African-American Community about End of Life Care?

Please order copies of *The African-American Spiritual and Ethical Guide to End of Life Care*!

Mail Requests to:

Gloria Anderson  
P. O. Box 30034  
Kansas City, MO 64112

Phone: (913) 433-3877

Email: gloria@hearttones.com  Website: www.hearttones.com

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