

# What Y'all Gon' Do With Me?

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

By Gloria Thomas Anderson, MSW

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# Purpose

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- ❑ 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

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- ❑ 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?

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- ❑ 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?

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- ❑ Racism in medicine has always existed and is deeply embedded in institutions, policies and personal mindsets.
  - The Tuskegee syphilis study (Chadwick, 1997)
  - Less use of cardiac procedures, reduced access to renal transplants, and fewer surgeries for lung cancer (Peterson, et al., 1997; Chen, et al., 2001; Bach, et al., 1999; Schulman, et al., 1999, Ayanian, et al., 1999)

# Barriers to Appropriate and Equitable Health Care and Everyday of Life

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- ❑ Biases
- ❑ Prejudice
- ❑ Stereotyping
- ❑ Discrimination
- ❑ Fear
- ❑ Ignorance
- ❑ Deception



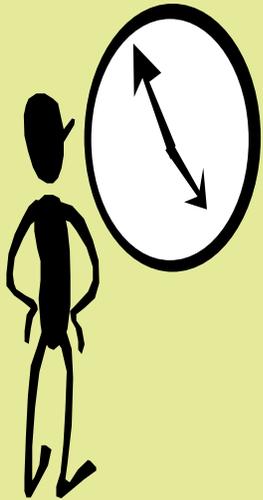
# Isn't It Time To Advocate For Real Change?

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"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

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- ❑ 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](http://www.people-press.org))
- ❑ Commission on Health Disparities and the Impact of Racism on African-American Health Status

# Social and Economic Factors Affect African-American EOL Decisions

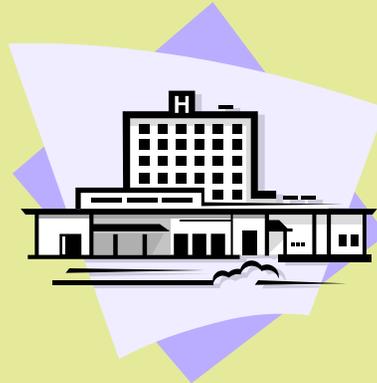
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1865-1872

1965-1975

(Hood, 2001)



Engrained  
Institutionalized  
Racism



The  
imbalance  
remains...

# Historical Perspective-Spirituality

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



# Religion vs. Spirituality

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- ❑ 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.

# Religion, Spirituality and the Church

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--50% of African Americans say they are “born again” or evangelical Protestants

(Pew Research Center, 2003)

--Religion and spiritual beliefs have been attributed to influencing the treatment preferences of African Americans in the face of illness (Johnson, Elbert-Avila & Tulskey, 2005)

# Recurrent Themes in African American Spiritual Beliefs

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- ❑ 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 & Tulskey, 2005)

# Universal Spiritual Values— Issues of the Spirit

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- Why me?
- What will happen to me?
- What has my life meant?

# Spirituality- A Sustaining Force

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- ❑ 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-

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- ❑ 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

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- ❑ 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

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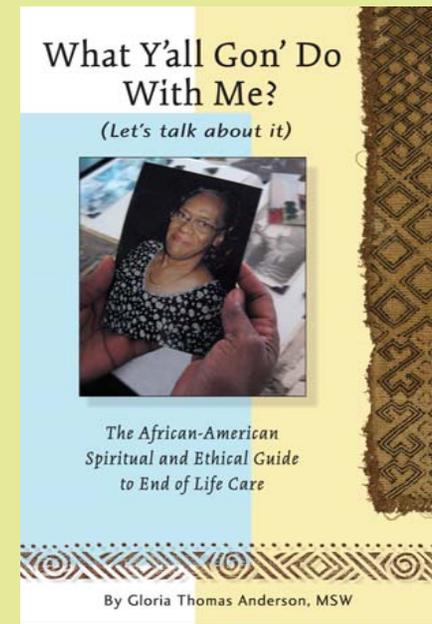
- ❑ To illustrate respectfulness and dignity to the patient's autonomy
- ❑ To include the critical conflicting moral and legal mandates
- ❑ To provide pertinent information and resources that could benefit the African American population

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

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Have you gotten your house  
in order?

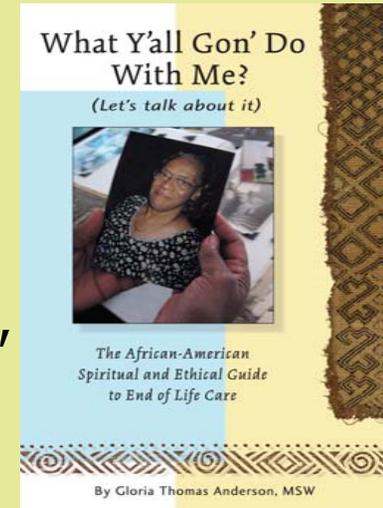
14 Important End of Life  
Issues You Want and  
Need To Know About



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

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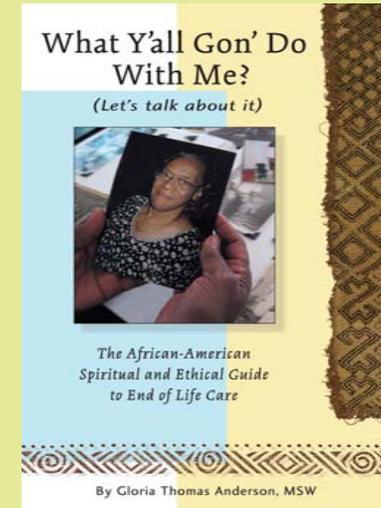
- Taking Control of Your Life and Health
- Gettin' Your House in Order
- More to Life than Being "Alive"



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

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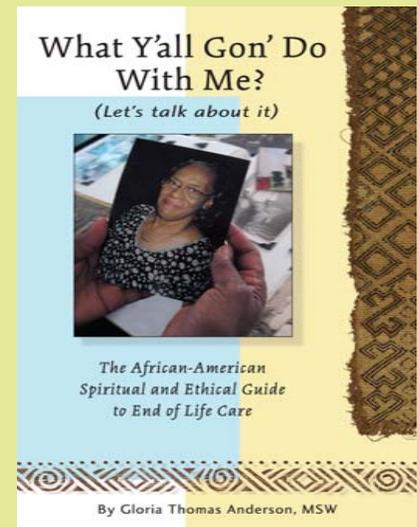
- The “F” Factor—Family, Friends and Foe
- The Healing Balm of Forgiveness
- Coping and Hoping—A Spiritual Journey
- What’s All This “End of Life” Stuff About?



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

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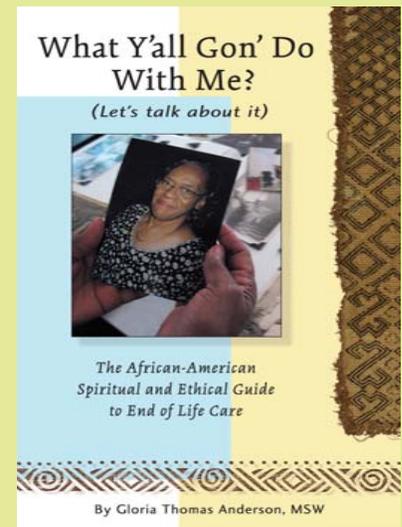
- Advance Directive Choices
- Planning for Emergency Situations, Even For People Who Are Not Terminally Ill
- 5 Important Things To Do



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

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



# Your Legacy—Your Life

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What's really important  
at the end of life?

- Building memories
- Leaving a legacy to be remembered by

# Embracing Life... Releasing Life

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## **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

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- 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!*

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# Acknowledgements

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- \* Black Health Community Fund, KCMO- travel grant
- \* The Center for Practical Bioethics- support and travel contribution.
- \* The UMKC Dept of Social Work-support and contribution.
- \* The UMKC Women's Council-Graduate Assistance Fund Award (grant to produce End of Life Guide project)
- \* Sarah Starnes, LCSW, VA Hospital, and other supportive VA staff in the final editing and production of the EOL Guide.
- \* Kimberly Johnson, MD, Duke University Medical Center
- \* Duke Institute on Care at the End of Life/The Divinity School Duke University, Durham, NC-research journal articles and resources.

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