



# Critical Issues in Urban Health

## Cultural Issues Associated with End of Life Treatment

Gloria Ramsey, JD, RN

Director, Community Outreach and Information Dissemination

Uniformed Services University of the Health Sciences  
Center for Health Disparities Research and Education

Associate Professor (nominee) Graduate School of Nursing  
Associate Research Professor (nominee) School of Medicine  
Department of Medical and Clinical Psychology

Copyright © 2006 by USU Center for Health Disparities Research and Education

# National Minority Health Month

- In 1914, Dr. Booker T. Washington, innovator, educator, health advocate, and most notably known as founder, president of Tuskegee University, he with the collective and individual efforts of other African American leaders who recognized the link between health, and social and economic well being, initiated Negro Health Improvement Week, which later became National Negro Health Week, April 1915, and then National Negro Health Movement.
- In October 2002, the 107th Congress passed a joint resolution (H.Con. Res. 388) to establish a National Minority Health and Health Disparities Month. This joint resolution reinvigorated health organizations and advocates nationally and locally to eliminate health disparities among vulnerable populations much like the movement in the early 1900's.



# Shirley Chisholm

Politics

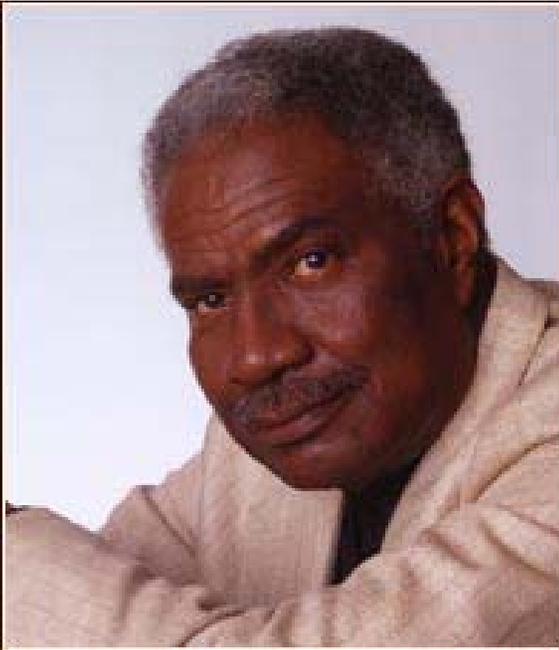
November 30, 1924 – January 01, 2005

Age: 80

Mrs. Chisholm, and her obituaries inevitably led, as she knew they would, with her litany of firsts -- first black woman in the House, first black woman to seek a major party presidential nomination.

Cause of Death:





# Ossie Davis

Actor, Writer, Director and Social Activist

December 18, 1917 – February 04, 2005

Age: 87

Actor Ossie Davis, who pioneered roles for African Americans in a stage and screen career that spanned more than 50 years. At the time of his death, the actor had been shooting the film "Retirement."

Cause of Death: Natural Causes



# Johnnie Cochran Jr.

Law

October 02, 1937 – March 29, 2005

Age: 67

Johnnie Cochran Jr., an attorney who rose to fame when he helped win an acquittal for O.J. Simpson in a double-murder trial.

Cause of Death: Brain Tumor



# Ronald Winans

Gospel Singer

June 30, 1956 – June 17, 2005

Age: 48

Ronald Winans, a Grammy-winning member of The Winans and of gospel's first family.

Cause of Death: Heart Attack

Copyright © 2006 by USU Center for Health Disparities Research and Education





# Renaldo "Obie" Benson

Entertainment

June 14, 1936 – July 1, 2005

Age: 69

Renaldo "Obie" Benson was an African-American soul and R&B singer and songwriter. He was best known as a member of Motown group The Four Tops. His last performance as a Four Top was on April 8, 2005 live on Late Night with David Letterman.

Cause of Death: Lung Cancer





# Luther Vandross

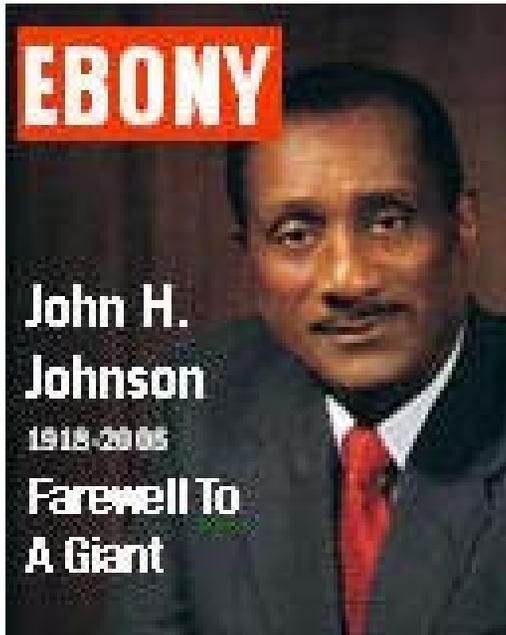
Music

April 20, 1951 – July 01, 2005

Age: 54

Grammy award winner Luther Vandross, whose deep, lush voice on such hits as "Here and Now" and "Any Love" sold more than 25 million albums while providing the romantic backdrop for millions of couples worldwide.

Cause of Death: Heart Attack/Stroke



# John H. Johnson

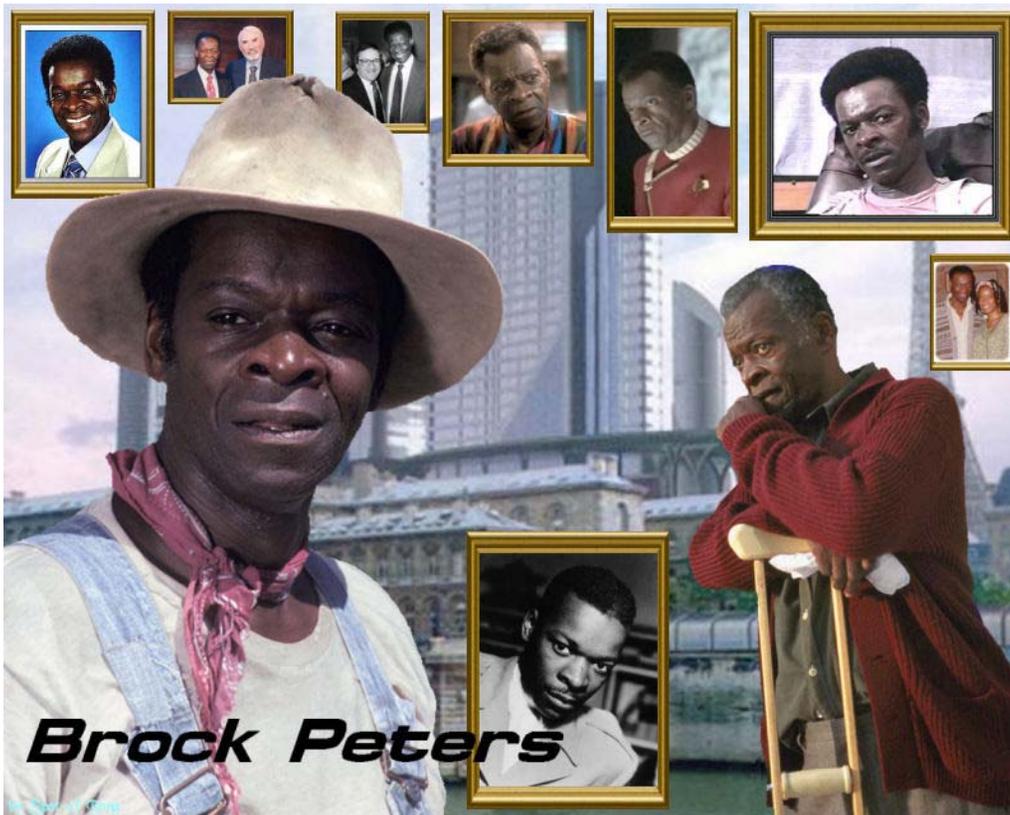
Publishing, Business

January 19, 1918 – August 08, 2005

Age: 87

Publisher John H. Johnson, whose Ebony and Jet magazines countered stereotypical coverage of blacks after World War II and turned him into one of the most influential black leaders in America.

Cause of Death: Heart Failure



# Brock Peters

Entertainment

July 02, 1927 – August 23, 2005

Age: 78

Actor Brock Peters, best known for his heartbreaking performance as the black man falsely accused of rape in "To Kill a Mockingbird."

Cause of Death: Pancreatic Cancer

A close-up portrait of Nipsey Russell, an African American man with a joyful expression, wearing a white shirt and a dark jacket. The background is dark and out of focus.

# Nipsey Russell

Entertainment

October 13, 1924 – October 02, 2005

Age: 80

Nipsey Russell, who played the Tin Man alongside Diana Ross and Michael Jackson in "The Wiz" as part of a decades-long career in stage, television and film.

Cause of Death: Cancer



# August Wilson

Theater

April 27, 1945 – October 02, 2005

Age: 60

Mr. Wilson was a Pulitzer Prize-winning American playwright. His singular achievement and literary legacy is a cycle of ten plays, each set in a different decade, depicting the comedy and tragedy of the African-American experience in the 20th century. Wilson's most famous plays are [Fences](#), [The Piano Lesson](#), [Ma Rainey's Black Bottom](#), and [Joe Turner's Come and Gone](#).

Cause of Death: Liver Cancer



# Rosa Parks

Social Activist

February 04, 1913 – October 24, 2005

Age: 92

Rosa Lee Parks, whose refusal to give up her bus seat to a white man sparked the modern civil rights movement.

Cause of Death: Natural Causes

# Richard Pryor

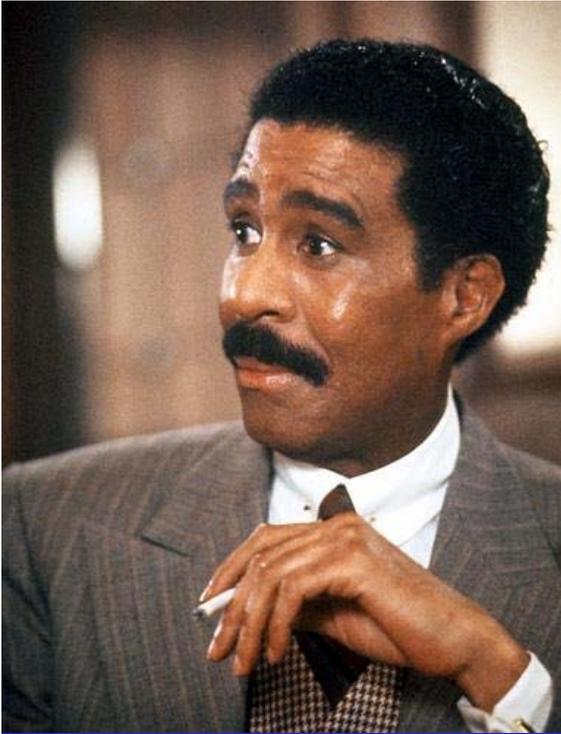
Actor-Comedian

December 01, 1940 – December 10, 2005

Age: 65

Richard Pryor, Considered one of the greatest, most influential comics of all time, showcased his skills in a trio of award-winning concert films--[Richard Pryor Live in Concert](#), [Richard Pryor Live on the Sunset Strip](#) and [Richard Pryor Here and Now](#) --and starred in more than 30 films, including [Silver Streak](#), [Uptown Saturday Night](#), [Stir Crazy](#) and the autobiographical comedy-drama [Jo Jo Dancer, Your Life Is Calling](#).

Cause of Death: Heart Attack



A portrait of Lou Rawls, an African American man with short dark hair, wearing a light-colored suit jacket over a red shirt. He is smiling slightly and looking towards the camera.

# Lou Rawls

Social Activist, Music

December 01, 1933 – January 06, 2006

Age: 72

Lou Rawls, who earned fame with his glorious voice and respect through his prodigious fundraising for the United Negro College Fund.

Starting as a church choir boy, Rawls ultimately applied those silky tones to a variety of musical genres and more, including movies, TV shows and commercials.

Cause of Death: Cancer

The Essentials

## Wilson Pickett



# Wilson Pickett

Music

March 18, 1941 – January 19, 2006

Age: 64

Alabama native and veteran soul singer Wilson Pickett, famed for his trademark screams, flaming delivery and flamboyant costumes, and known for such hits as "Mustang Sally" and "In the Midnight Hour."

Cause of Death: Heart Attack



# Fayard Nicholas

Entertainment

October 20, 1914 – January 24, 2006

Age: 91

Fayard Nicholas, who with his brother Harold wowed the tap dancing world with their astonishing athleticism and who inspired generations of dancers, from Fred Astaire to Savion Glover.

Cause of Death: Pneumonia/  
complications of a Stroke



# Coretta Scott King

Social Activist

April 27, 1927 – January 30, 2006

Age:78

Coretta Scott King, who surged to the forefront of the fight for racial equality after her husband Martin Luther King Jr. was murdered in 1968.

Cause of Death: Stroke/Heart Attack/  
Ovarian Cancer

# Ask Yourself

## Are these Faces of Disparity



# Defining Disparities...

The term “racial and ethnic health disparities” is an umbrella term that includes disparities in *health* and disparities in *health care*.

*Disparities in health*: differences between two or more population groups in health outcomes and in the prevalence, incidence, or burden of disease, disability, injury, or death.

*Disparities in health care*: differences between two or more population groups in health care access, coverage, and quality of care, including differences in preventive, diagnostic, and treatment services.

# ...Defining Health Disparities

- Institute of Medicine (IOM)
  - racial or ethnic differences in the quality of healthcare that are not due to access related factors or clinical need.
- Synonyms for disparity
  - inequality, unlikeness, disproportion or difference.

(National Health Care Disparities Report-Executive Summary)

# Racial and Ethnic Health Disparities

- The problem of racial and ethnic health disparities has been well documented, leading the U.S. Department of Health and Human Services (HHS) to make eliminating health disparities by 2010 a national goal.

## ...Racial and Ethnic Health Disparities...

- Socially and economically challenged persons are often at a disadvantage to access health information, including end of life education, and they often die in pain and suffer needlessly
- America has a responsibility to all its people

## ...Racial and Ethnic Health Disparities

- ALL Americans have a right to compassionate, quality end of life care
- Age, gender, socioeconomic status, sexual orientation, ethnicity, culture, diagnosis or prognosis should not interfere with that right

# Benefits of Cultural Competence...

- Health Professional Organizations and State Laws Require for CME Requirements
- Patients feel empowered and respected
- Patients have increased awareness of proposed medical treatments and available options

# Benefits of Cultural Competence

- Patients from various cultural groups are more willing to seek and receive appropriate care, thus reducing health disparities
- Patients report greater satisfaction with the health care system

# Minority Populations are Disproportionately Affected

---

- Cardiac Disease
- Cancer Screening and Management
- Diabetes
- HIV Infections/AIDS
- Immunizations
- Infant mortality

# Racial and Ethnic Influences on End-of-Life Preferences

- Reluctance of blacks and Hispanics to use hospice services (8% AA)
- Reluctance of blacks and Hispanics to complete advance directives (20% generally)
- Reluctance of blacks and Hispanics to withdraw life-sustaining treatment
- Race/ethnicity is a predictor of end of life decision-making (even when adjust for demographic and socioeconomic status)
- Black physicians remained more likely than non-Hispanic whites to choose aggressive treatment options (Mebane, 1999)
- Religion/religiosity/spirituality associated with measures to prolong life, reluctance to withdraw life support, and disapproval of assisted suicide
- Women are more likely to experience more pain and be undertreated for pain.
- Women are less likely than men to prefer and receive aggressive treatment at the end of life

# Barriers to Palliative and End-of-Life Care...

- History and Heritage
  - Legacy of slavery
  - Abuses in medical experimentation
  - Economic Injustices
  - Racial profiling practices
  - Disproportionate numbers of incarceration
  - Societal and ethical misconduct
  - General loss of credibility of institutions

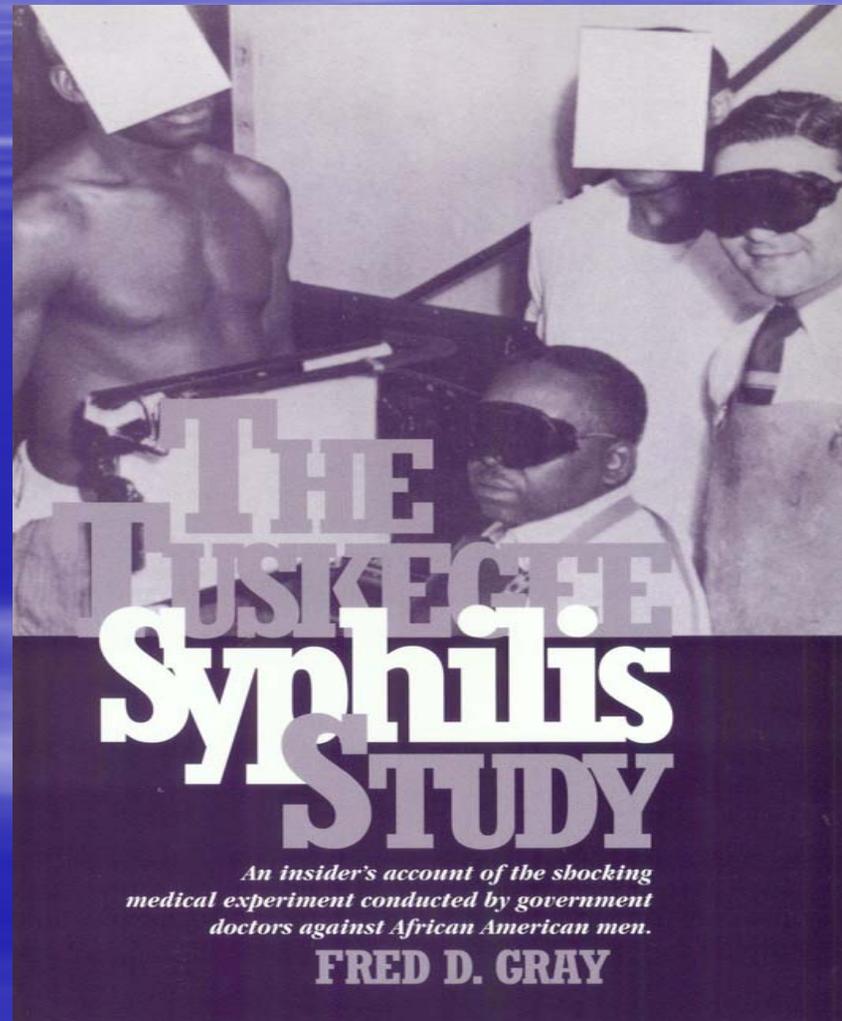
# ...Barriers to Palliative and End-of-Life Care...

- Religion and Spirituality
  - Pain and suffering is to be endured as part of a spiritual commitment.
  - Many African-Americans believe that suffering is redemptive.
  - To avoid suffering could be seen as failing a “test of faith” ... because the experience is being sent by God to test one’s faith.
  - Nobility of suffering (struggle and survival).

# ...Barriers to Palliative and End-of-Life Care...

- Breach of Trust
  - The bioethics and medical literature suggest that cultural mistrust is a major factor in advance care planning for African Americans.
  - These conclusions are unsubstantiated...more research must be done.
  - Individuals and institutions must work toward change to ensure that minority patients begin to trust.

# ...Barriers to Palliative and End-of-Life Care...



# ...Barriers to Palliative and End-of-Life Care...

- Education
  - African Americans like the general population lack knowledge about the kind of care offered through palliative or hospice programs.
  - Physicians lack knowledge of the range of issues related to palliative and end-of-life care.
  - African American physicians care for more minority patients than do other physicians and this impacts upon the community in which it serves.

# ...Barriers to Palliative and End-of-Life Care...

- Education

- Clergy lack knowledge of the range of issues related to palliative and end-of-life care.
- Clergy are often called to assist members with death and dying; however, they lack the skills to help family make treatment decisions that are deemed aggressive, intrusive and futile.
- Clergy education may help foster effective partnerships with physicians and other health care professionals.

# APPEAL

A Progressive Palliative Care Educational  
Curriculum for the Care of African Americans  
at Life's End

**Patient Centered Decision Making  
(Advance Care Planning)**

# What are Advance Directives?...

- Advance directives are legal documents in which you give oral and written instructions about your health care if, in the future, you become unable to speak for yourself.
- Each state regulates the use of advance directives differently.
- Advance directives should only be used when it is determined that the individual is incompetent or lacks decision making capacity.

# Definitions and Benefits of Advance Care Planning

## Definitions:

- Process of planning for future medical care
- Values and goals are explored and documented
- Determine proxy decision maker
- Professional, legal responsibility

## Benefits:

- Increased trust towards the health care provider
- Reduced uncertainty
- Less confusion and conflict
- Peace of mind

# Types of Advance Directives...

- Living Will
- Durable Power of Attorney for Health Care (i.e., health care proxy, health care agent, attorney-in-fact, or surrogate)

# Gloria Ramsey

## Nurse-Attorney

Uniformed Services University of the Health Sciences, Maryland  
Formerly, NYU Division of Nursing, New York



- A Durable Power of Attorney for Health Care names a person to make decisions when you are unable to.
- A Living Will provides instructions on paper to providers.

# Statutory Variations in Advance Directives

- Both federal and state laws govern the use of advance directives
- Federal law is 1990 enacted the Patient Self Determination Act (PSDA)
- All 50 states and DC have laws authorizing use of advance directives
- Laws vary from state to state
- Obtain state specific forms:

[www.caringinfo.org](http://www.caringinfo.org)

[www.nhpco.org](http://www.nhpco.org)

1-800-658-8898

Other documents that embraces the  
spirit of  
**Advance Directives**

- Verbal statements
- Personal letter or value statement indicating preferences
- Documents developed to address values and are legally binding (i.e, Five Wishes)  
[www.agingwithdignity.org](http://www.agingwithdignity.org)
- Do Not Hospitalize or Do Not Transfer Orders

# CULTURAL DIFFERENCES

**Dying is an event  
that is deeply  
influenced by  
cultural mores  
and  
practices**

**Bethsheba Johnson**  
Nurse Practitioner  
Luck HIV/AIDS Care Center, Illinois



- African American Patients are suspicious of Advance directives.

# 6 steps for successful advance care planning

1. Why the topic
2. Introduce the topic
3. Engage in structured discussions
4. Document patient preferences
5. Review, update
6. Apply directives when need arises

# Step 1: Why the topic...

Explain that you discuss advance directives and advance care planning with ALL patients.

# Richard Payne

Physician

Duke Center Care at the End of Life/  
Co-Founder Initiative to Improve Palliative Care for  
African Americans, North Carolina



- African American and Latino patients know that they can be treated differently in the health care system.
- “Are you talking to Mrs. Sally down the hall about this?”

# ...Step 1: Why the topic

- Tell patient they are not dying, if they are not
- Allow time to process information
- Tell patient they have time to think about it and do not have to make a decision that moment
- Allow time to build trust
- Address issues of cultural paranoia and distrust
- Explore and discuss cultural values and behaviors
- Discuss effects of not making a decision  
(Rx, family)

## Step 2: Introduce the topic...

- Be straightforward and routine
- Be prepared to introduce and reintroduce topic over time
- Identify a health care professional of the same race to speak with patient and family, when possible
- Health care professionals should be sensitive to the cultural values, beliefs and perceptions of the patient and family

**Edwina Taylor**  
Nurse Practitioner

Balm in Gilead Cooper Green Hospital, Alabama



- Advance Directives are hard to get –  
“I look like a white woman trying to rush you to your death –”

## ...**Step 2: Introduce the topic**

- Determine patient familiarity
- Explain the process
- Determine comfort level
- Determine health care proxy, if any
- Determine person who makes decisions
- Revisit the process as often as needed

**Mrs. Ginger Bryant**  
Onlok Senior Center Client  
San Francisco, California



- She knows she “doesn’t want all those tubes in her.”
- She doesn’t have a formal advance directive.

# Howard Spiller

Chicago, Illinois



- Placing Advance Care planning on the “problem list” and reviewing it in regular clinical sessions improves the process and allows patients to exercise autonomy.

# Advance Care Planning Includes Informed Consent

- Nature of the illness
- Recommended treatment
- Reasonable alternatives
- Chance of each alternative achieving its intended goal
- Burdens, benefits of each alternative

# Step 3: Engage in Structured Discussions

- Proxy decision maker(s) present
- Describe scenarios, options for care
- Elicit patient's values, goals
- Allow time for discussion
- Be available to answer questions
- Check for inconsistencies and issues that need clarification

# Sydney Weinstien

Family Caregiver/Beautician-Business Owner  
San Francisco, California



- I see (Advance Directives) as a guide for my daughter.
- Daughters are often time the child most relied upon.

# Role of the Health Care Proxy

- Aware of request to act as proxy
- Entrusted to speak for the patient
- Involved in the discussions
- Must be willing and able to assume the responsibility of the proxy role
- Able to jealously advocate

**Eledie Watson Stone**  
Home /Hospice Nurse Specialist  
Fremont, California



- Believes her family knows what she wants.

# Kaye

Outreach Coordinator/ EOL Care Researcher  
University of Alabama  
Center for Palliative Care, Alabama



- If you want to talk advance directives do it with the whole family.

# Edwina Taylor

Nurse Practitioner

Balm in Gilead Cooper Green Hospital, Alabama



- Define key medical terms in language the patient, proxy and/or family understands;
- Terminology counts - e.g., allow natural death is better language than DNR.

## Step 4: Document Patient Preferences...

- Review advance directive
- Advise health care proxy and family
- Sign the documentation
- Enter into the medical record
- Recommend statutory documents
- Ensure portability (state to state as well as in and out-of- hospital orders)

# Gloria Ramsey

## Nurse-Attorney

Uniformed Services University of the Health Sciences, Maryland  
Formerly, NYU Division of Nursing, New York



- African Americans are less likely to complete advance directives... lots of speculation -- including suspicion of “writing things down....”

# Determination of Decision-Making Capacity...

- Clinical Determination
- Mental Status Test
- Functional Capability
  - Patient understands own right to make a choice
  - Patient understands the medical situation
  - Patient can communicate
  - Patient's decision is consistent and stable over time
- Decision-Specific Capacity
- Reassess after each decision

# When a Patient Lacks Capacity ...

- Proxy decision-maker
- Sources of information
  - written advance directives
  - patient's verbal statements
  - patient's general values and beliefs
  - how patient lived his / her life
  - best interest determinations

# Step 5: Review, Update

- Follow up periodically
- Note major life events
- Discuss, document changes
- Discuss status of the health care proxy/agent/attorney-in-fact/surrogate
- Withholding vs. Withdrawing Treatment

# Life Sustaining Treatments: Withholding vs. Withdrawing

- Starvation... the term carries emotional overtones, implying the physically uncomfortable process and the spectrum of physical changes that healthy and hungry persons undergo if they are involuntarily deprived of food
- No evidence that terminal dehydration is a painful process

## S.J. Williams

Family Care Giver/Quality of Life Consultant  
Los Angeles, California



- “...It’s bad for the living to let people starve to death.”

# Step 6: Apply Directives...

- Determine applicability
- Read and interpret the advance directive
- Consult with the health care proxy (health care agent, attorney-in-fact, surrogate) and spiritual advisor

# Yusef Shaheen

Iman, Masgid Mosque  
Washington, DC



- People are more conscientious about religious practice near the end of life and accommodations need to be made for this.

# Gloria Ramsey

## Nurse-Attorney

Uniformed Services University of the Health Sciences, Maryland  
Formerly, NYU Division of Nursing, New York



- Many African Americans choose their minister as proxy -- ministers need help to shoulder the burden and fight the health care system.

# ...Step 6: Apply Directives

- Consult with Ethics Committee for disagreements. Committee members should be sensitive to the values of the patient and family
- Carry out the treatment plan

# Common Barriers to Advance Care Planning

- Lack of trust
- Fear
- Hopelessness
- Inadequate knowledge
- Inability to identify with providers
- Lack of medical insurance
- Secrecy of medical condition

# Common Barriers to Advance Care Planning

- Lack of information
- Failure to plan
- Healthcare Proxy absent for discussions
- Unclear patient preferences
- Focus too narrow
- Communicative patients are ignored
- Making assumptions

# Patient Centered Decision-Making

## Key Take-Home Points. . .

- Advance care planning and or patient centered decision making is a process and not a “one shot deal.” Thus, multiple conversations may occur before decisions are made, if at all.

# Key Take-Home Points. . .

- Every person has a personal sense of how he or she would like to live and die that will be based on personal, cultural, spiritual and religious values, belief, and preferences.
- Most patients welcome the opportunity to discuss their preferences with their physician or health care provider.
  - Every person has the right to participate in the planning of his or her own healthcare.

**Dianne Deese**  
Hospice Administrator  
Vitas Hospice, Illinois



- We need to teach patients that Advance Directives can be empowering.

# Conclusion

- African Americans do complete advance directives if provided the information by trusted sources and given sufficient time to process, understand and feel comfortable with the information.



# Implications for Health Care Professionals

- Engage patients, family members or surrogates in authentic dialogue to enable them to emerge from their cultural silence to define their own reality and make choices.
- Advance directives is a process and not an event. Continue to follow through and follow up with patients and families because African Americans complete directives.

# Dr. Martin Luther King, Jr. - 1966



“Of all the forms of inequality, injustice in health is the most shocking and inhumane.”

# Contact Information

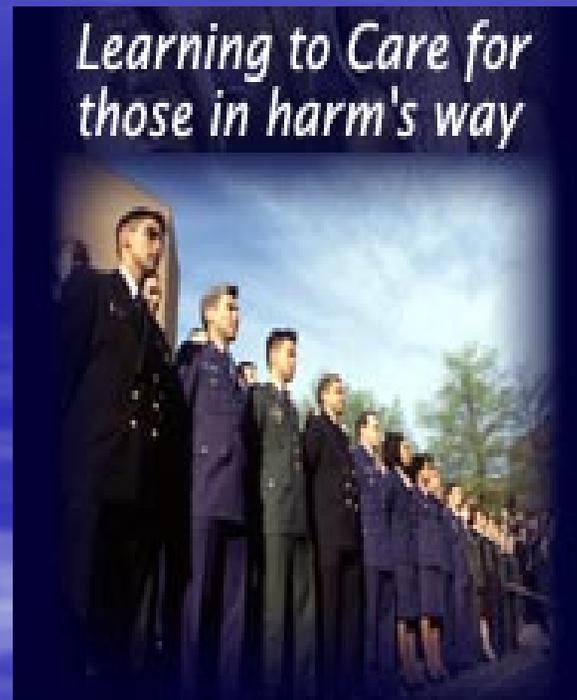
Gloria Ramsey, JD, RN  
Director, Community Outreach and  
Information Dissemination  
Uniformed Services University  
Center for Health Disparities  
Research and Education  
8484 Georgia Avenue, Suite 950  
Silver Spring, MD 20910

Tel: (301) 589-1175 x16

Fax: (301) 589-5569

Email: [gramsey@usuhs.mil](mailto:gramsey@usuhs.mil)

[www.usuhs.mil](http://www.usuhs.mil)



INTENTIONALLY

LEFT

BLANK

The African American Church and  
Community Perspectives on End-of-Life Care:  
*An Educational Initiative for Urban Ministers, Lay Faith Leaders and  
Health Professionals Caring for African Americans*



Gloria C. Ramsey, RN, JD  
Godfrey Gregg, MSW, PhD (c)  
Marie Taylor, RN, MA  
New York University  
College of Nursing

*Funded by the Fan Fox and Leslie R. Samuels Foundation, Inc.*

Copyright © 2006 by USU Center for Health Disparities Research and Education

# Religious Institutions and African Americans...

- The church is an important institution for African-Americans of all ages, but especially the elderly
- Historically, black churches provided a wide range of resources and opportunities that were inaccessible to African-Americans from mainstream institutions

# Goals of the Project...

- Draw on African Americans' confidence in their religious institutions in order enhance their awareness about advance directives, advance care planning and organ and tissue donation.
- Construct an educational program that is culturally, linguistically, and spiritually sensitive about advance directives, advance care planning and organ and tissue donation.



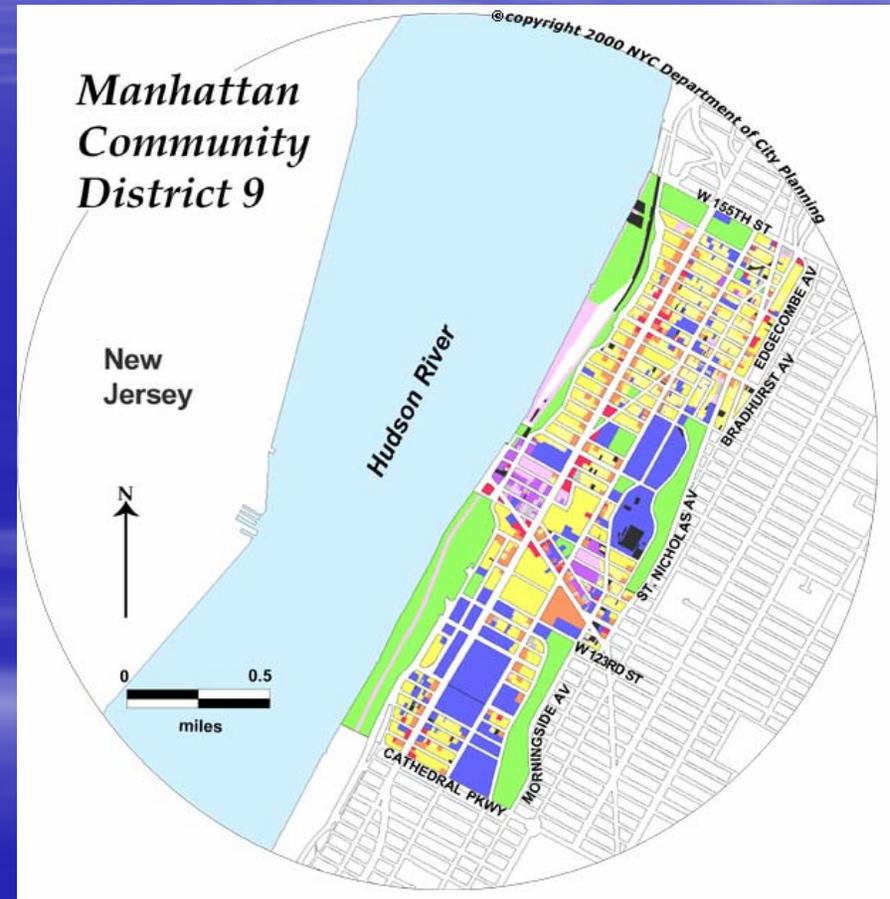
# ...Goals of the Project...

- Increase the rate of advance directive completion among older African Americans.



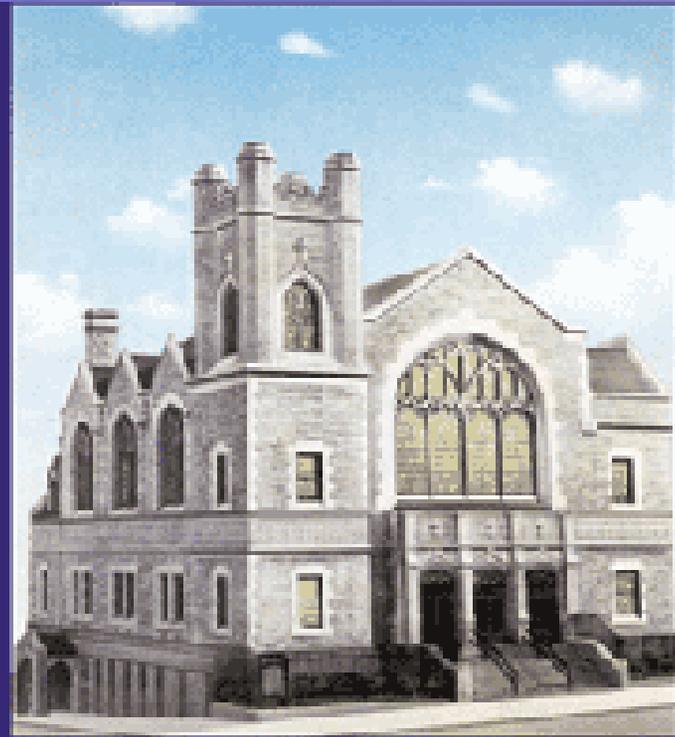
# Location: Why Harlem?

- The total population of West Harlem is 111,724
- African Americans number 34,924 and make up 31% of the population
- They are the second largest ethnic group in the district
- 11,072 people, or 9.9% of these are 65 years of age and over.



# Why Convent Avenue Baptist Church?

- Large urban population
  - over 2000 people attend
  - holds 3 services every Sunday
  - smaller churches may not give a large enough pool of potential participants
  - large concentration of African Americans



Rev. Clarence P. Grant, DD, Pastor  
429 West 145th Street | New York, NY 10032  
Telephone: (212)234-6767 | Fax: (212)234-6019  
E-mail: [Conventchurch@aol.com](mailto:Conventchurch@aol.com)

# Why Convent Avenue Baptist Church?

- Already existing methods of training within the church
  - Spiritual Big Brothers and Big Sisters Ministry
  - Sunday School classes which range from Kindergarten to Adults
  - Children's Ministry
  - Mentoring Ministry
  - Young Adult Ministry
  - Sister 2 Sister
  - Parents Ministry
  - Parish Nurse Ministry or Health Ministry



# Methods

The project has Three Phases:

- Phase I: Congregation Survey & Focus Groups

Phase II: Educational Training

- Phase III: Dissemination

# Opening Doors, Building Bridges and “Getting In”...

## Preparation for Project

- Personal Values (Self Assessment, Passion, Commitment)
- Demonstrate that you Care
- Identify a Respected Member of the Community
- Meet with “Community Leader” (RFP, Recruitment Process, Incentives for Participation)
- Attend events regularly (be seen and learn practices of group)
- Inquire who might also be included and informed about project

# Opening Doors, Building Bridges ...and “Getting In”...

## Conducting Project

- Meet with “Community Leader” (RFP, Recruitment Process, Incentives for Participation)
- Identify team members with similar backgrounds, where possible
- Attend events regularly (be seen and learn practices of group)
- Develop Trust (‘Trusted Interpreters’ of Data)

# Opening Doors, Building Bridges ...and “Getting In”...

## Conducting Project

- Project Timelines and Community Timelines May Differ
- Be prepared to participate in activities that are important to the group

# Methods

The project has Three Phases:

- Phase I: Congregation Survey & Focus Groups

Phase II: Educational Training

- Phase III: Dissemination

# The African American Church and Community Perspectives for End of Life Care: An Educational Initiative for Urban Ministers, Lay Faith Leaders and Health Care Professionals Caring for African Americans

## Who We Are

Researchers from New York University Division of Nursing, in collaboration with the Health Ministry of Convent Avenue Baptist Church, are doing a study about ways to assure that people are able to make their own health care decisions. The project seeks to provide a better understanding of the health care decision making process for African Americans.

## What Can You Do to Help?

- We need your help in the following three (3) ways:
1. **Congregation Survey** – Please fill out the survey in your bulletin and put it in the drop box in the walkway after service, or leave it in the "drop box" in the Education Building during the week.
  2. **Focus Groups** – Please participate in our focus groups (a small group discussion where people share their opinions and insights on certain issues). To do so please either call, complete and return the attached form to the "drop box in the walkway" or sign up in the walkway after service or during the week in the Education Building. The focus groups will last 1½ to 2 hours. A light dinner will be served.
  3. **Educational Training Program** – Learn how you can start caring conversations with your loved ones. Please join us in educational training sessions where you learn about Health Care Proxies, Living Wills, Durable Power of Attorney for Health Care, and additional information about end of life care matters. A light dinner will be served.

**Survey**

*Piece of Mind*

*Help Your Family*



**WHO MAKES DECISIONS FOR YOU IF YOU'RE HOSPITALIZED, BECOME SICK OR FAINT?  
DID YOU KNOW THAT IF YOU BECAME ILL YOUR FAMILY MIGHT NOT BE ABLE TO MAKE DECISIONS FOR YOU?**

Please join us in the upcoming weeks as we sit and talk about these important questions.

Mario Taylor, RN, MA  
Convent Avenue Baptist Church  
Parish Nurse  
(212) 234-6767

Gloria Ramsey, RN, JD  
New York University  
Project Director  
(212) 998-5356

**Focus Groups**

*Help your Doctor Decide*

*Don't a Family Conflict*



Food will be served

# ...Phase I: Congregational Survey

**The African American Church and  
Community Perspectives for End of Life Care:  
An Educational Initiative for Urban Ministers, Lay Faith Leaders and  
Health Professionals Caring for African Americans**

## Congregation Survey

1. Are you?

- Male  
 Female

2. Do you live alone?

- Yes  
 No

3. What year were you born?  
\_\_\_\_\_

4. How often do you attend  
religious services?

- Never  
 Rarely  
 Occasionally  
 Regularly

5. What kind of work do you  
do?

- Professional  
 Technical  
 Service  
 Sales  
 Clerical  
 Other: \_\_\_\_\_

6. What is your main  
ethnic/racial group?

- Black/African  
American  
 Latino of \_\_\_\_\_  
descent  
 Black of \_\_\_\_\_  
descent  
 Other (specify)  
\_\_\_\_\_

7. What kind of health  
insurance do you have?  
Check ALL that apply

- none  
 through current  
employer  
 self pay  
 Medicare  
 Medicaid  
 HMO/PPO  
 other federal/  
military subsidy

8. Have you ever heard the  
words "advance directive"?

- Yes

9. Have you talked to your  
loved ones about how you  
want to be cared for at the  
end of life?

- Yes  
 No

10. Do you have a signed  
Living Will, [a document where  
you write down what your wishes  
are for treatment should you be  
unable to make them yourself]; or  
Durable Power of Attorney  
for Health Care (Health Care  
Proxy), [a document in which  
you appoint someone to make  
treatment decisions for you should  
you be unable to make them  
yourself. Treatment may include  
starting your heart if it stops  
beating, using a breathing machine,  
and tube feeding]?

- Yes, Living Will  
 Yes, Health Care  
Proxy  
 Yes, Both  
 No  
 Don't know

11. Have you signed an  
Organ Donation Card?

- Yes  
 No

12. Would you complete a  
Health Care Proxy if consent  
for organ donation were  
included?

- Yes  
 No

# Phase I: Focus Groups...

## Church Bulletin

*Piece of Mind*

Marie Taylor, RN, MA  
Convent Avenue Baptist Church  
Parish Nurse  
(212) 234-6767

*Help your family*

### Make it Better!

Researchers from NYU Division of Nursing, in collaboration with the Health Ministry, are doing a study about ways to assure that people are able to make their own health care decisions. The project seeks to provide a better understanding of the health care decision making process for African Americans. We need your help in the following two ways:

1) **Congregational Survey** – Please fill out the survey attached and put it in the “drop box” in the walkway after service, or leave it in the “drop box” in the Education Building during the week;

and

2) **Focus Groups** – Please participate in our focus groups (a small group discussion where people share their opinions and insights on certain issues). To do so please either *call*; complete and return the attached form to the “drop box” in the walkway; The focus groups will last 1 ½ to 2 hours. A light dinner will be served.

If you have further questions, please feel free to contact us.

Gloria Ramsey, RN, JD  
New York University  
Project Director  
(212) 998-5356

*Don't want to cause  
a family conflict*

*Help your doctor decide*

The African American Church and  
Community Perspectives for End of Life Care:  
*An Educational Initiative for Urban Ministers, Lay Faith Leaders and  
Health Professionals Caring for African Americans*

Name \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_

Zip: \_\_\_\_\_

Best times to reach you:

Morning  Afternoon  Evening

Phone Number(s) ( ) \_\_\_\_\_-\_\_\_\_\_

( ) \_\_\_\_\_-\_\_\_\_\_

**YES**, I want to participate

Please detach and return to the “drop box” labeled **FOCUS  
GROUPS** located in the walkway.

# ...Phase I: Focus Groups...

- Participants
  - Women's Fellowship
  - Men's Fellowship
  - Health and Wholeness Ministry
  - Deacons
  - Sick and Shut-In
  - Ministers

# ...Phase I: Focus Groups...

- Logistics
  - Telephone interested participants
  - Confirm attendance (1-3 days prior)
  
- Day of meeting
  - Food (culturally appropriate)
  - Donation to church
  - Provide consent forms, executive summary and survey
  - Open meeting with prayer

# ... Phase I: Focus Group Survey...

Questions (same as Congregation Survey )

- If you were terminally ill, where would you like to die?
- List persons whose death had a significant impact on you.
- How familiar are you with hospice service?
- How familiar are you with palliative care?

## ...Focus Groups...

- 2 hours in duration
- Tape Recorded
- Weekdays (6:00 p.m.-8:00 p.m.) or Saturday (10:00 a.m.-12:00 p.m.)
- Held at the church
- During February and March 2003
- Severe Winter

# ...Common Themes...

- Lack of Trust
- Lack of Education
- Daughters were identified as significant decision makers and care givers
- Church is the right place to teach health education
- The phenomena of food is important in the engagement process

# Thank You Celebration

- Reported back to the church our findings
- Member check
- Presented and acknowledge the parish nurse and the deacon supervisor of the Health and Wholeness Ministry
- Provide Certificates of Appreciation to all who participated in the focus groups
- Publish findings in the church newspaper

# Phase II: Educational Training

- Advisory Board Meeting
- Five hour Training
- Held at the Church
- Saturday was the preferred d



**WHO MAKES DECISIONS FOR YOU IF YOU'RE HOSPITALIZED,  
BECOME SICK OR FAINT?**



**DID YOU KNOW THAT IF YOU BECAME ILL YOUR FAMILY MIGHT NOT BE  
ABLE TO MAKE DECISIONS FOR YOU?**

Join us for educational training sessions where you learn about how you can start "Caring Conversations" with loved ones. Learn about Health Care Proxies, Living Wills, Do-Not-Resuscitate Orders, Hospice, Palliative Care, Taking Care of Yourself to Take Care of Others, and the Affects of Grief and Bereavement for Traumatic, Natural and Sudden Death.

Please call or complete this form and return it to the "drop box" labeled "Training" in the walkway after the 8 am and 11 am services:

**Marie Taylor, RN, MA**  
Parish Nurse  
Convent Avenue Baptist Church  
(212) 234-6767



**Gloria Ramsey, RN, JD**  
Project Director  
New York University  
(212) 998-5356

**Food will be Served**

The African American Church and Community Perspective on End-of-Life Care:  
An Educational Initiative for Urban Ministers, Lay Faith Leaders  
and Health Professionals Caring for African Americans

Name: \_\_\_\_\_

Best Times To Reach You:  Morning  Afternoon  Evening

Phone Number(s): (    ) \_\_\_\_\_ - \_\_\_\_\_ (    ) \_\_\_\_\_ - \_\_\_\_\_

**Best Times For Training (indicate 1, 2, 3, 4 by order of preference):**

Month: \_\_ Mid-August    \_\_ Mid-September    \_\_ Mid-October    \_\_ Mid-November

Day and Time:  Tuesday, 6:30 pm – 8:30 pm & Thursday, 6:30 pm – 9:00 pm  
OR

Saturday, 9:00 am – 2:00 pm (includes breaks)

# ...Phase II...

The Training Sessions, derived from the focus groups, addressed:

1. Taking Charge of Your Health Care
2. What Happens When You Die?
3. Spirituality
4. Grief and Bereavement
5. End of Life Care Decision-Making
6. Organ and Tissue Donation



# Taking Charge of Your Health Care

At the end of this session, you will be able to:

- Understand how to have “caring conversations” with loved ones.
- Identify the leading causes of death among African Americans.
- Define Advance Directives.
- Discuss Life Sustaining Treatments.
- Discuss the importance of Advance Care Planning.

# What Happens When You Die?

At the end of this session, you will be able to:

- Define death.
- Describe the process of dying.
- Describe the signs and symptoms as death approaches.
- Identify physical, psychological, social and spiritual care needs for an imminently dying patient and his/her family.

# Spirituality

At the end of this session, you will be able to:

- Discuss the spiritual beliefs of African Americans.
- Describe your faith, spirituality and prayer during times of illness.
- Identify your spiritual beliefs concerning the end of life.

# Grief and Bereavement

At the end of this session, you will be able to:

- ⑩ Understand grief, loss, mourning and bereavement during traumatic, natural and sudden death.
- ⑩ Describe the mourning process.
- ⑩ Identify the impact suffering has on the individual, family and caregiver at the end of life.
- ⑩ Identify ways to help yourself and to help others during the time of grief and loss.
  - Identify local resources to support coping with grief and bereavement

# Organ and Tissue Donation

At the end of this session, you will be able to:

- Discuss “fact and myths” about organ donation
- State five (5) reasons that African Americans are reluctant to donate.
- List three (3) Bible scriptures supporting organ and tissue donation.
- Discuss the benefits of organ and tissue donation.
- Articulate who and what is the New York Organ Donor Network.

# End-of-Life Decision Making

At the end of this session, you will be able to:

- ⑩ Define Advance Directives.
- ⑩ Define Do Not Resuscitate Orders (DNR).
- ⑩ Define Hospice and Palliative Care.
- ⑩ Complete a Living Will and Health Care Proxy.

# End-of-Life Decision Making

At the end of this session, you will be able to:

- Identify characteristics of an effective proxy.
- Discuss caregiver's stress and ways to cope.
- Identify local resources to support quality end-of-life care.

# FIVE WISHES<sup>®</sup>

MY WISH FOR:

**The Person I Want to Make Care Decisions for Me When I Can't**

**The Kind of Medical Treatment I Want or Don't Want**

**How Comfortable I want to Be**

**How I Want People to Treat Me**

**What I Want My Loved Ones to Know**

NAME

DATE

ADDRESS

CITY

STATE

ZIP

Website: [www.agingwithdignity.org](http://www.agingwithdignity.org)

Copyright © 2006 by USU Center for Health Disparities Research and Education

# Five Wishes

*There are many things in life that are out of our hands. This Five Wishes booklet gives you a way to control something very important—how you are treated if you get seriously ill. It is an easy-to-complete form that lets you say exactly what you want. Once it is filled out and properly signed it is valid under the laws of most states.*

## What Is Five Wishes?

Five Wishes is the first living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. It lets you choose the person you want to make health care decisions for you if you are not able to make them for yourself. Five Wishes lets you say exactly how you wish to be

treated if you get seriously ill. It was written with the help of The American Bar Association's Commission on the Legal Problems of the Elderly, and the nation's leading experts in end-of-life care. It's also easy to use. All you have to do is check a box, circle a direction, or write a few sentences.

## How Five Wishes Can Help You And Your Family

- It lets you talk with your family, friends and doctor about how you want to be treated if you become seriously ill.
- Your family members will not have to guess what you want. It protects them if you become seriously ill, because they won't have to make hard choices without knowing your wishes.
- You can know what your mom, dad, spouse, or friend wants through a Five Wishes living will. You can be there for them when they need you most. You will understand what they really want.

## How Five Wishes Began

For 12 years, a man named Jim Towey worked closely with Mother Teresa, and, for one year, he lived in a hospice she ran in Washington, DC. Inspired by this first-hand experience, Mr. Towey sought a way for patients and their families to plan ahead and to cope with serious

illness. The result is Five Wishes and the response to it has been overwhelming. It has been featured on CNN and NBC's Today Show and in the pages of *Time* and *Money* magazines. Newspapers have called Five Wishes the first "living will with a heart."

## Who Should Use Five Wishes

Five Wishes is for anyone 18 or older — married, single, parents, adult children, and friends. Over one million Americans of all ages have already used it. Because it

works so well, lawyers, doctors, hospitals and hospices, churches and synagogues, employers, and retiree groups are handing out this document.

## Five Wishes States

If you live in the District of Columbia or one of the 35 states listed below, you can use Five Wishes and have the peace of mind to know that it substantially meets your state's requirements under the law:

Arizona	Hawaii	Minnesota	North Dakota
Arkansas	Idaho	Mississippi	Pennsylvania
California	Illinois	Missouri	Rhode Island
Colorado	Iowa	Montana	South Dakota
Connecticut	Louisiana	Nebraska	Tennessee
Delaware	Maine	New Jersey	Virginia
District of Columbia	Maryland	New Mexico	Washington
Florida	Massachusetts	New York	West Virginia
Georgia	Michigan	North Carolina	Wyoming

If your state is not one of the 35 states listed here, Five Wishes does not meet the technical requirements in the statutes of your state. So some doctors in your state may be reluctant to honor Five Wishes. However, many people from states not on this list do complete Five Wishes along with their state's legal form. They find that Five Wishes helps them express all that they want and provides a helpful guide to family members, friends, care givers and doctors. Most doctors and health care professionals know they need to listen to your wishes no matter how you express them.

## How Do I Change To Five Wishes?

You may already have a living will or a durable power of attorney for health care. If you want to use Five Wishes instead, all you need to do is fill out and sign a new Five Wishes as directed. As soon as you sign it, it takes away any advance directive you had before. To make sure the right form is used, please do the following:

- Destroy all copies of your old living will or durable power of attorney for health care. Or you can write "revoked" in large letters across the copy you have. Tell your lawyer if he or she helped prepare those old forms for you. *AND*
- Tell your Health Care Agent, family members, and doctor that you have filled out the new Five Wishes. Make sure they know about your new wishes.

## WISH 1

### The Person I Want To Make Health Care Decisions For Me When I Can't Make Them For Myself.

*If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my Health Care Agent (or other term that may be used in my state, such as proxy, representative, or surrogate). This person will make my health care choices if both of these things happen:*

- My attending or treating doctor finds I am no longer able to make health care choices, AND
- Another health care professional agrees that this is true.

*If my state has a different way of finding that I am not able to make health care choices, then my state's way should be followed.*

#### The Person I Choose As My Health Care Agent Is:

First Choice Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_ City/State/Zip \_\_\_\_\_

If this person is not able or willing to make these choices for me, OR is divorced or legally separated from me, OR this person has died, then these people are my next choices:

Second Choice Name \_\_\_\_\_ Third Choice Name \_\_\_\_\_

Address \_\_\_\_\_ Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_ City/State/Zip \_\_\_\_\_

Phone \_\_\_\_\_ Phone \_\_\_\_\_

#### Picking The Right Person To Be Your Health Care Agent

Choose someone who knows you very well, cares about you, and who can make difficult decisions. A spouse or family member may not be the best choice because they are too emotionally involved. Sometimes they are the best choice. You know best. Choose someone who is able to stand up for you so that your wishes are followed. Also, choose someone who is likely to be nearby so that they can help when you need them. Whether you choose a spouse, family member, or friend as your Health Care Agent, make sure you talk about these wishes and be sure that this person agrees to respect

and follow your wishes. Your Health Care Agent should be **at least 18 years or older** (in Colorado, 21 years or older) and should **not** be:

- Your health care provider, including the owner or operator of a health or residential or community care facility serving you.
- An employee of your health care provider.
- Serving as an agent or proxy for 10 or more people unless he or she is your spouse or close relative.

*I understand that my Health Care Agent can make health care decisions for me. I want my Agent to be able to do the following: (Please cross out anything you don't want your Agent to do that is listed below.)*

- Make choices for me about my medical care or services, like tests, medicine, or surgery. This care or service could be to find out what my health problem is, or how to treat it. It can also include care to keep me alive. If the treatment or care has already started, my Health Care Agent can keep it going or have it stopped.
- Interpret any instructions I have given in this form or given in other discussions, according to my Health Care Agent's understanding of my wishes and values.
- Arrange for admission to a hospital, hospice, or nursing home for me. My Health Care Agent can hire any kind of health care worker I may need to help me or take care of me. My Agent may also hire a health care worker, if needed.
- Make the decision to request, take away or not give medical treatments, including artificially-provided food and water, and any other treatments to keep me alive.
- See and approve release of my medical records and personal files. If I need to sign my name to get any of these files, my Health Care Agent can sign it for me.
- Move me to another state to get the care I need or to carry out my wishes.
- Authorize or refuse to authorize any medication or procedure needed to help with pain.
- Take any legal action needed to carry out my wishes.
- Donate useable organs or tissues of mine as allowed by law.
- Apply for Medicare, Medicaid, or other programs or insurance benefits for me. My Health Care Agent can see my personal files, like bank records, to find out what is needed to fill out these forms.
- Listed below are any changes, additions, or limitations on my Health Care Agent's powers.

#### If I Change My Mind About Having A Health Care Agent, I Will

- Destroy all copies of this part of the Five Wishes form. OR
- Tell someone, such as my doctor or family, that I want to cancel or change my Health Care Agent. OR
- Write the word "Revoked" in large letters across the name of each agent whose authority I want to cancel. Sign my name on that page.

## WISH 2

### My Wish For The Kind Of Medical Treatment I Want Or Don't Want.

*I believe that my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and any other directions I have given to my Health Care Agent, to be respected and followed.*

#### What You Should Keep In Mind As My Caregiver

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.
- I do not want anything done or omitted by my doctors or nurses with the intention of taking my life.
- I want to be offered food and fluids by mouth, and kept clean and warm.

#### What "Life-Support Treatment" Means To Me

Life-support treatment means any medical procedure, device or medication to keep me alive. Life-support treatment includes: medical devices put in me to help me breathe; food and water supplied by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions; dialysis; antibiotics;

and anything else meant to keep me alive. If I wish to limit the meaning of life-support treatment because of my religious or personal beliefs, I write this limitation in the space below. I do this to make very clear what I want and under what conditions.

---



---



---



---

#### In Case Of An Emergency

If you have a medical emergency and ambulance personnel arrive, they may look to see if you have a **Do Not Resuscitate** form or bracelet. Many states require a person to have a **Do Not Resuscitate** form filled out and

signed by a doctor. This form lets ambulance personnel know that you don't want them to use life-support treatment when you are dying. Please check with your doctor to see if you need to have a **Do Not Resuscitate** form filled out.

*Here is the kind of medical treatment that I want or don't want in the four situations listed below. I want my Health Care Agent, my family, my doctors and other health care providers, my friends and all others to know these directions.*

#### Close to death:

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

#### In A Coma And Not Expected To Wake Up Or Recover:

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

---



---



---



---

#### Permanent And Severe Brain Damage And Not Expected To Recover:

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I can not speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

#### In Another Condition Under Which I Do Not Wish To Be Kept Alive:

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write "end-stage condition." That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)

*The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers. I also do not expect these wishes to excuse my doctor or other health care providers from giving me the proper care asked for by law.*

### WISH 3

#### My Wish For How Comfortable I Want To Be.

(Please cross out anything that you don't agree with.)

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
- If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
- I wish to have a cool moist cloth put on my head if I have a fever.
- I want my lips and mouth kept moist to stop dryness.
- I wish to have warm baths often. I wish to be kept fresh and clean at all times.
- I wish to be massaged with warm oils as often as I can be.
- I wish to have my favorite music played when possible until my time of death.
- I wish to have personal care like shaving, nail clipping, hair brushing, and teeth brushing, as long as they do not cause me pain or discomfort.
- I wish to have religious readings and well-loved poems read aloud when I am near death.

### WISH 4

#### My Wish For How I Want People To Treat Me.

(Please cross out anything that you don't agree with.)

- I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.
- I wish to have my hand held and to be talked to when possible, even if I don't seem to respond to the voice or touch of others.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my church or synagogue told that I am sick and asked to pray for me and visit me.
- I wish to be cared for with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.

### WISH 5

#### My Wish For What I Want My Loved Ones To Know.

(Please cross out anything that you don't agree with.)

- I wish to have my family and friends know that I love them.
- I wish to be forgiven for the times I have hurt my family, friends, and others.
- I wish to have my family, friends and others know that I forgive them for when they may have hurt me in my life.
- I wish for my family and friends to know that I do not fear death itself. I think it is not the end, but a new beginning for me.
- I wish for all of my family members to make peace with each other before my death, if they can.
- I wish for my family and friends to think about what I was like before I became seriously ill. I want them to remember me in this way after my death.
- I wish for my family and friends and caregivers to respect my wishes even if they don't agree with them.
- I wish for my family and friends to look at my dying as a time of personal growth for everyone, including me. This will help me live a meaningful life in my final days.
- I wish for my family and friends to get counseling if they have trouble with my death. I want memories of my life to give them joy and not sorrow.
- After my death, I would like my body to be (circle one): buried or cremated.
- My body or remains should be put in the following location\_\_\_\_\_.
- The following person knows my funeral wishes: \_\_\_\_\_.

If anyone asks how I want to be remembered, please say the following about me:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

If there is to be a memorial service for me, I wish for this service to include the following (list music, songs, readings or other specific requests that you have):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(Please use the space below for any other wishes. For example, you may want to donate any or all parts of your body when you die. Please attach a separate sheet of paper if you need more space.)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Signing The Five Wishes Form

*Please make sure you sign your Five Wishes form in the presence of the two witnesses.*

I, \_\_\_\_\_, ask that my family, my doctors, and other health care providers, my friends, and all others, follow my wishes as communicated by my Health Care Agent (if I have one and he or she is available), or as otherwise expressed in this form. This form becomes valid when I am unable to make decisions or speak for myself. If any part of this form cannot be legally followed, I ask that all other parts of this form be followed. I also revoke any health care advance directives I have made before.

Signature: \_\_\_\_\_ Social Security Number: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Date: \_\_\_\_\_

### Witness Statement • (2 witnesses needed):

I, the witness, declare that the person who signed or acknowledged this form (hereafter "person") is personally known to me, that he/she signed or acknowledged this [Health Care Agent and/or Living Will form(s)] in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT:

- The individual appointed as (agent/proxy/surrogate/patient advocate/representative) by this document or his/her successor,
- The person's health care provider, including owner or operator of a health, long-term care, or other residential or community care facility serving the person,
- An employee of the person's health care provider,
- Financially responsible for the person's health care,
- An employee of a life or health insurance provider for the person,
- Related to the person by blood, marriage, or adoption, and,
- To the best of my knowledge, a creditor of the person or entitled to any part of his/her estate under a will or codicil, by operation of law.

*(Some states may have fewer rules about who may be a witness. Unless you know your state's rules, please follow the above.)*

Signature of Witness #1	Signature of Witness #2
Printed Name of Witness	Printed Name of Witness
Address	Address
Phone	Phone

### Notarization • Only required for residents of Missouri, North Carolina, Tennessee and West Virginia

- If you live in Missouri, only your signature should be notarized.
- If you live in North Carolina, Tennessee or West Virginia, you should have your signature, and the signatures of your witnesses, notarized.

STATE OF \_\_\_\_\_

COUNTY OF \_\_\_\_\_

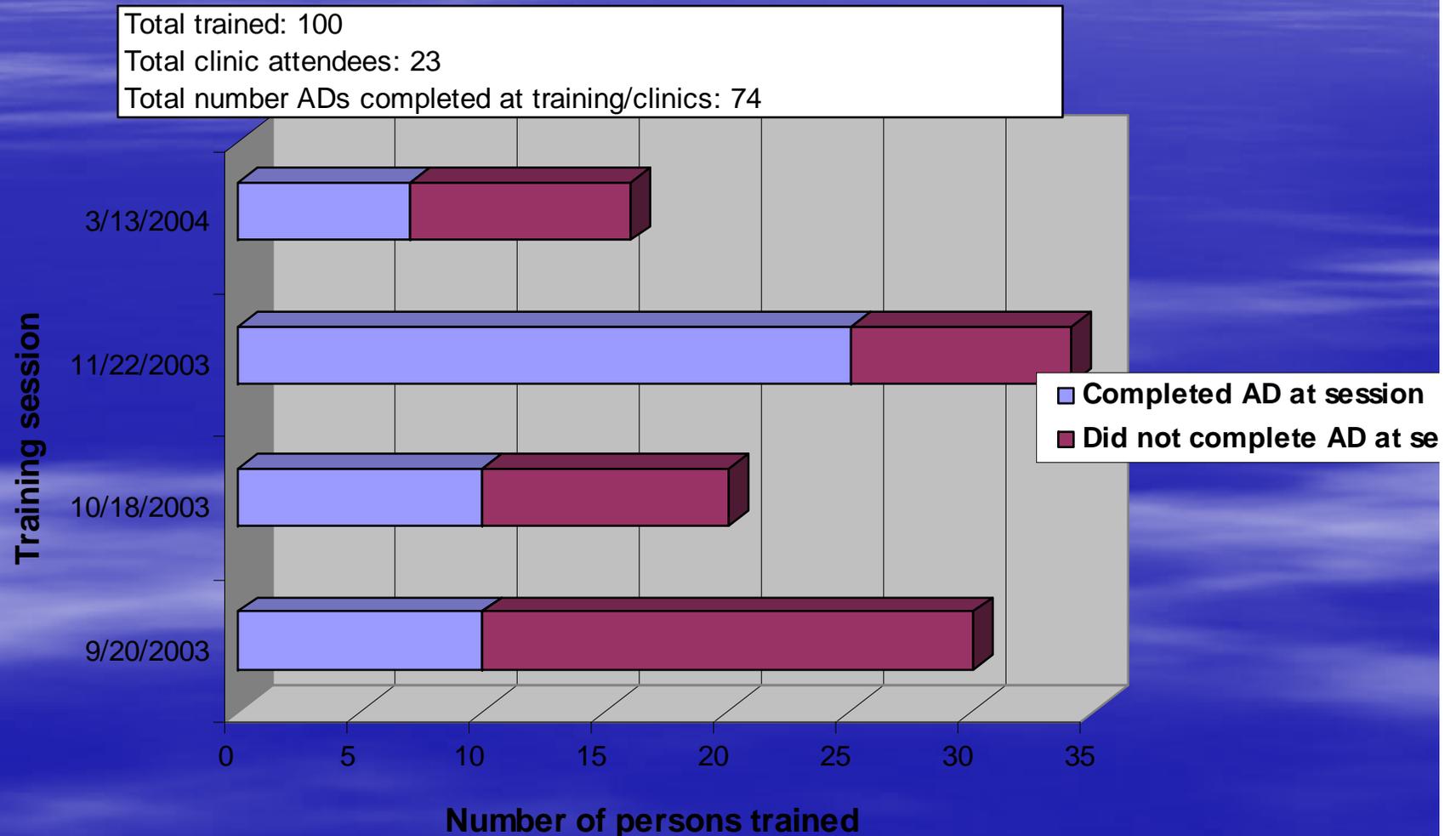
On this \_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, the said \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_, known to me (or satisfactorily proven) to be the person named in the foregoing instrument and witnesses, respectively, personally appeared before me, a Notary Public, within and for the State and County aforesaid, and acknowledged that they freely and voluntarily executed the same for the purposes stated therein.

My Commission Expires: \_\_\_\_\_

\_\_\_\_\_  
Notary Public

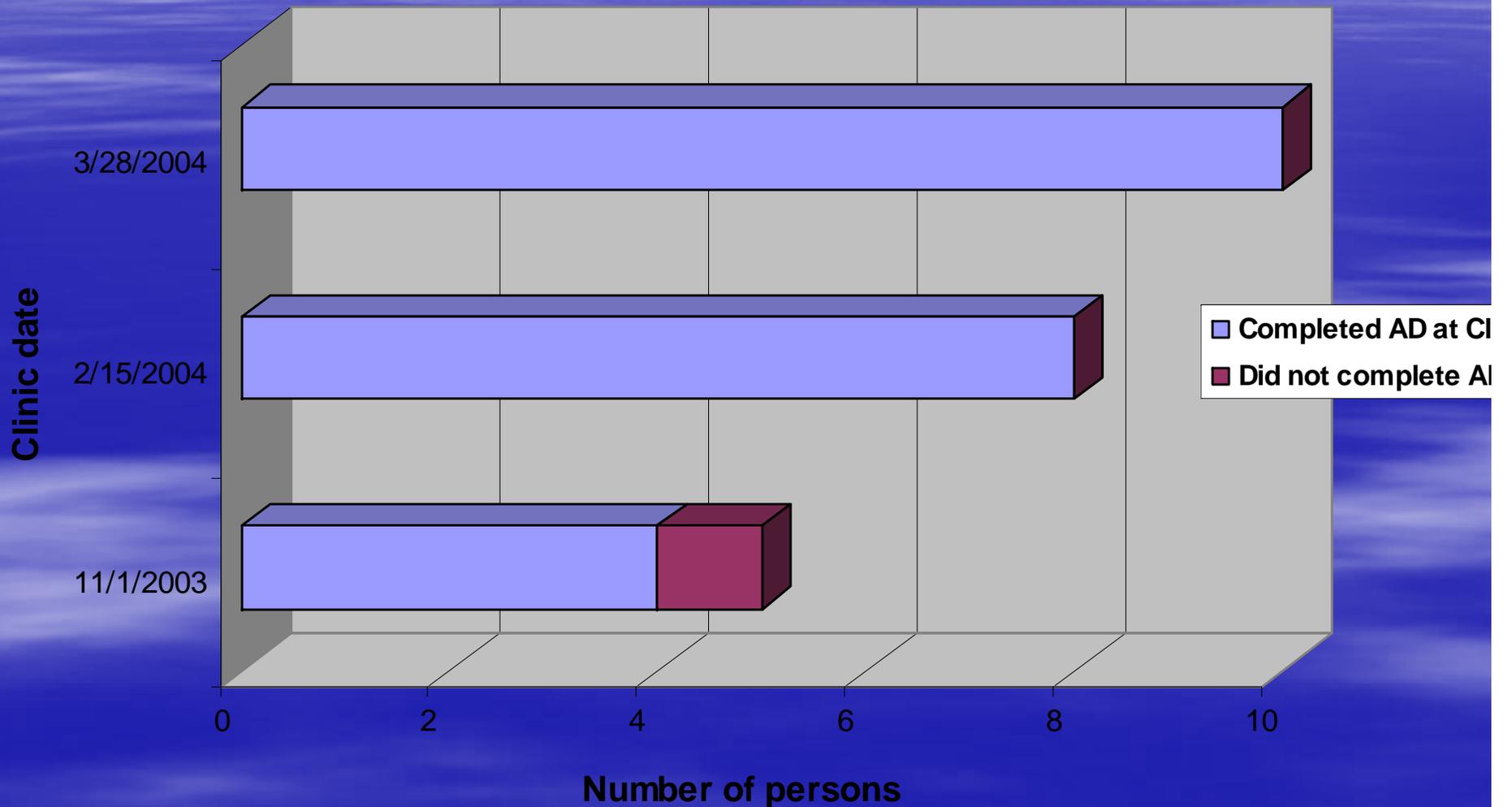
# Phase II Results

## Attendance of Training Sessions and Advance Directive (AD) Completion

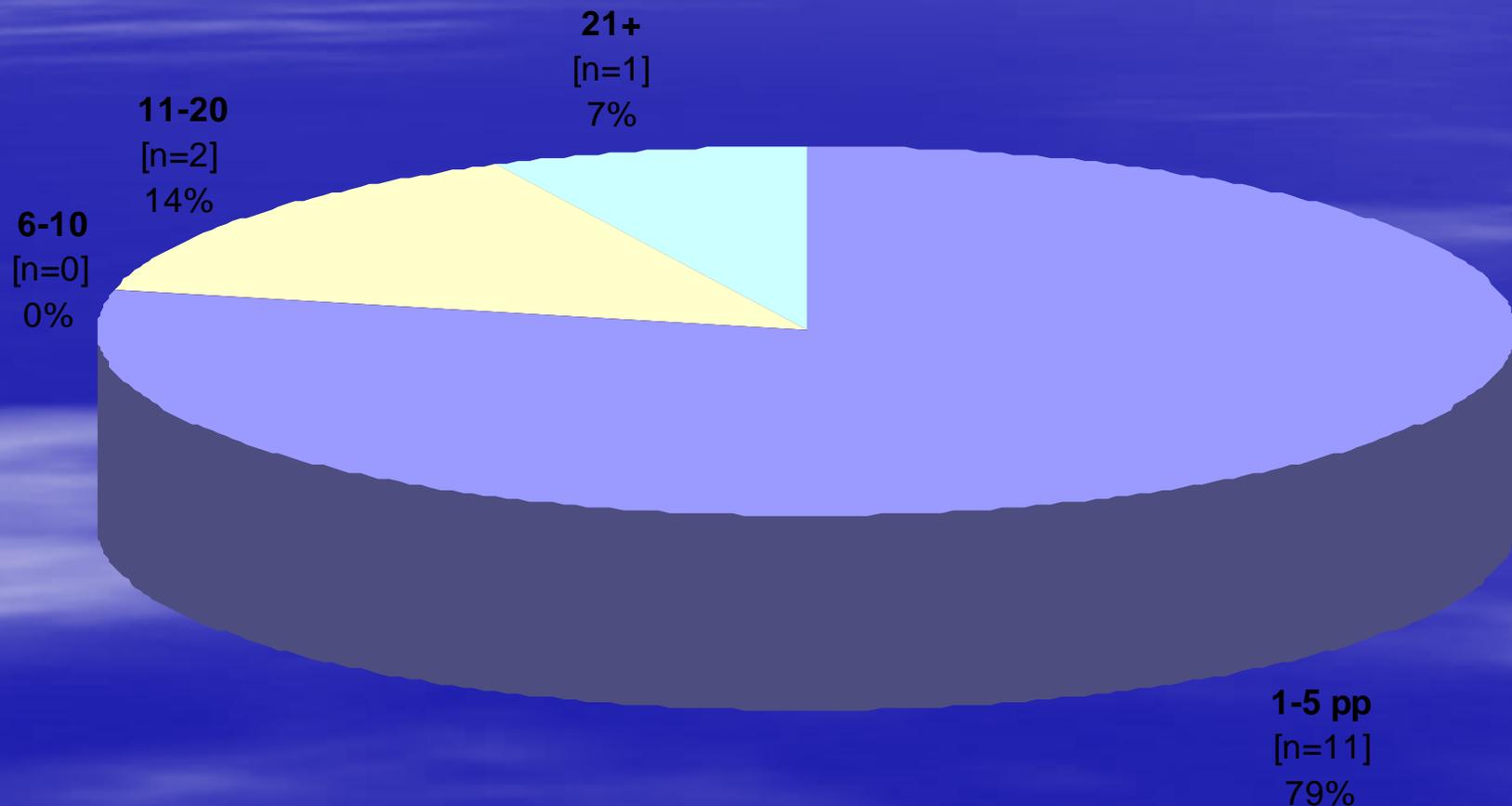


## Clinic Attendance and Advance Directive (AD) Completion

Total trained: 100  
Total clinic attendees: 23  
Total number ADs completed at training/clinics: 74



## Responses to Follow-up Question: Do you know how many people you told completed an advance directive?



# Opening Doors, Building Bridges ...and “Getting In”

## After Project

- Report back to the group
- Strengthen Trust (‘Trusted Interpreters’ of Data)
- Invite someone who benefited from the project to be an advocate

# Conclusion

- African Americans do complete advance directives if provided the information by trusted sources and given sufficient time to process, understand and feel comfortable with the information.



# Implications for Health Care Professionals

- Engage patients, family members or surrogates in authentic dialogue to enable them to emerge from their cultural silence to define their own reality and make choices.
- Advance directives is a process and not an event. Continue to follow through and follow up with patients and families because African Americans complete directives.

# Dr. Martin Luther King, Jr. - 1966



“Of all the forms of inequality, injustice in health is the most shocking and inhumane.”

# Contact Information

Gloria Ramsey, JD, RN  
Director, Community Outreach and  
Information Dissemination  
Uniformed Services University  
Center for Health Disparities  
Research and Education  
8484 Georgia Avenue, Suite 950  
Silver Spring, MD 20910

Tel: (301) 589-1175 x16

Fax: (301) 589-5569

Email: [gramsey@usuhs.mil](mailto:gramsey@usuhs.mil)

[www.usuhs.mil](http://www.usuhs.mil)

