



African-American Outreach

Pine Bluff Pilot Project and Survey Results



Our mission is to enhance the
quality of life for those facing
serious illness and loss by

Why African Americans?

surrounding them with love and
embracing them with the best
in physical, emotional, and
spiritual care.



Our mission is to enhance the
quality of life for those facing
serious illness and loss by

“It’s all about the mission.”

Michael Aureli

embracing them with the best
in physical, emotional, and
spiritual care.



**“African Americans and other minorities
How is this our mission, specifically?
are at greater risk of not dying well.”**

Duke Divinity School Professor Richard Payne



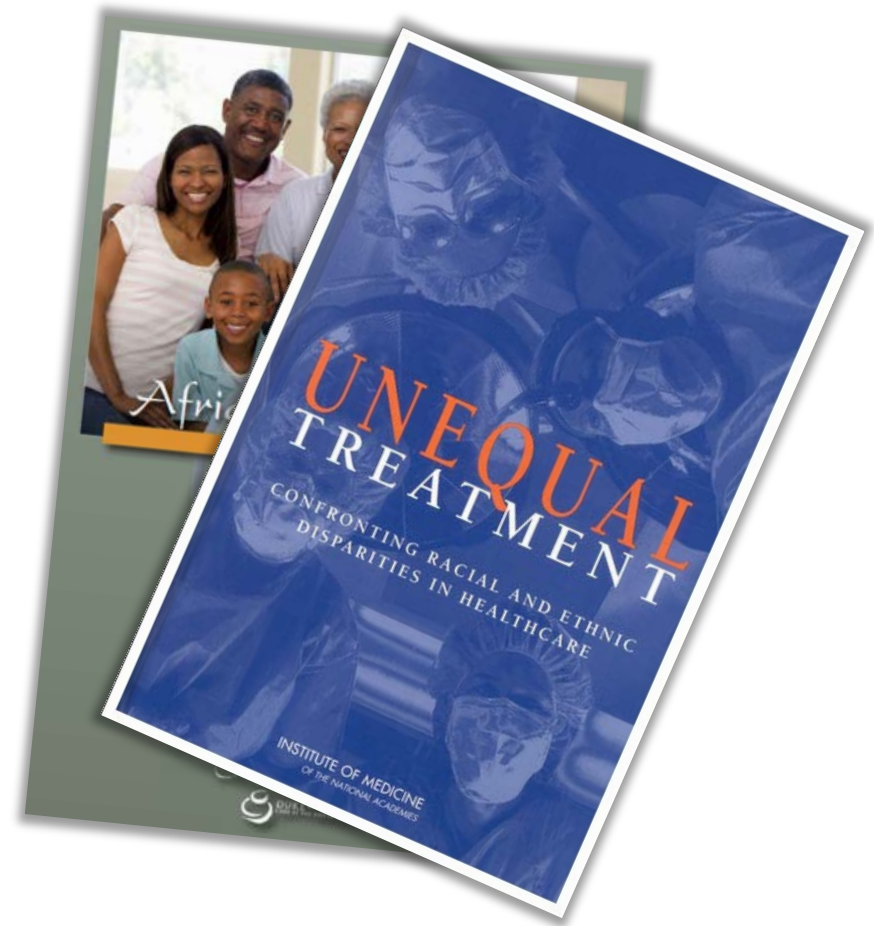
**“African Americans and other minorities
are at greater risk of not dying well.”**

Duke Divinity School Professor Richard Payne



Institute of Medicine Study

- Race alone accounts for disparate rates of medical treatment.
- African Americans are dying from treatable and preventable illnesses with more frequency than other ethnic groups.
- Show higher rates of disease and more likely to die.
- Countless examples of African American patients experiencing discrimination.



NHPCO Outreach Guide

African Americans are a vulnerable population:

- Lower incomes and educational attainment.
- Higher poverty and unemployment.
- Less likely to be married and more likely women head-of-households, and caring for grandchildren.
- Less health insurance, lower life expectancy, & higher infant mortality.
- Largest concentration (55%) in the South.



NHPCO – History Matters

- Just three generations from slavery.
- Many still remember segregation, Jim Crow, and violence against them.
- Deeply distrustful of government and health care system.
- 2003 study showed ~50% of African American respondents believed AIDS was a plot to exterminate blacks. (See Tuskegee Experiment)
- Regarding health care, especially at the end of life, “it is little wonder that many worry that hospice is just another way to hasten death.”



NHPCO Outreach Guide

“Black people still don’t believe in the political process, because the process has never served us. We’ve been betrayed by the political process, betrayed by the medical process, betrayed by each and every process in America, and it’s all based on racism. That distrust affects our entire personality in a great many ways.”

African American Focus Group Member



NHPCO Outreach Guide

“Among African Americans, non-acceptance of advance directives appears to be part of a much broader pattern of values regarding quality of life, as well as a historical legacy of segregation. Do Not Resuscitate (DNR) orders may be viewed as a way of limiting expensive healthcare or as cutting costs by ceasing care prematurely. Historically, this perspective may stem from a long history of distrust of the white-dominated healthcare system.”

Searight & Gafford, *American Family Physician* 2005



Duke University Study

- AH Participants, 2015 – Linda Bateman, Dena Duckworth, Amy Thomason, and John Yarbrough.
- Why African Americans use hospice less – barriers:
 1. Knowledge – less exposed to information, more misconceptions, like hospice is a place to die or means giving up.
 2. More likely to want life sustaining therapies.
 3. More spiritual beliefs – only God can decide, even suffering part of God's plan, advance care planning not needed.
 4. Legacy of mistrust.



 **Department of Medicine**
Duke University School of Medicine

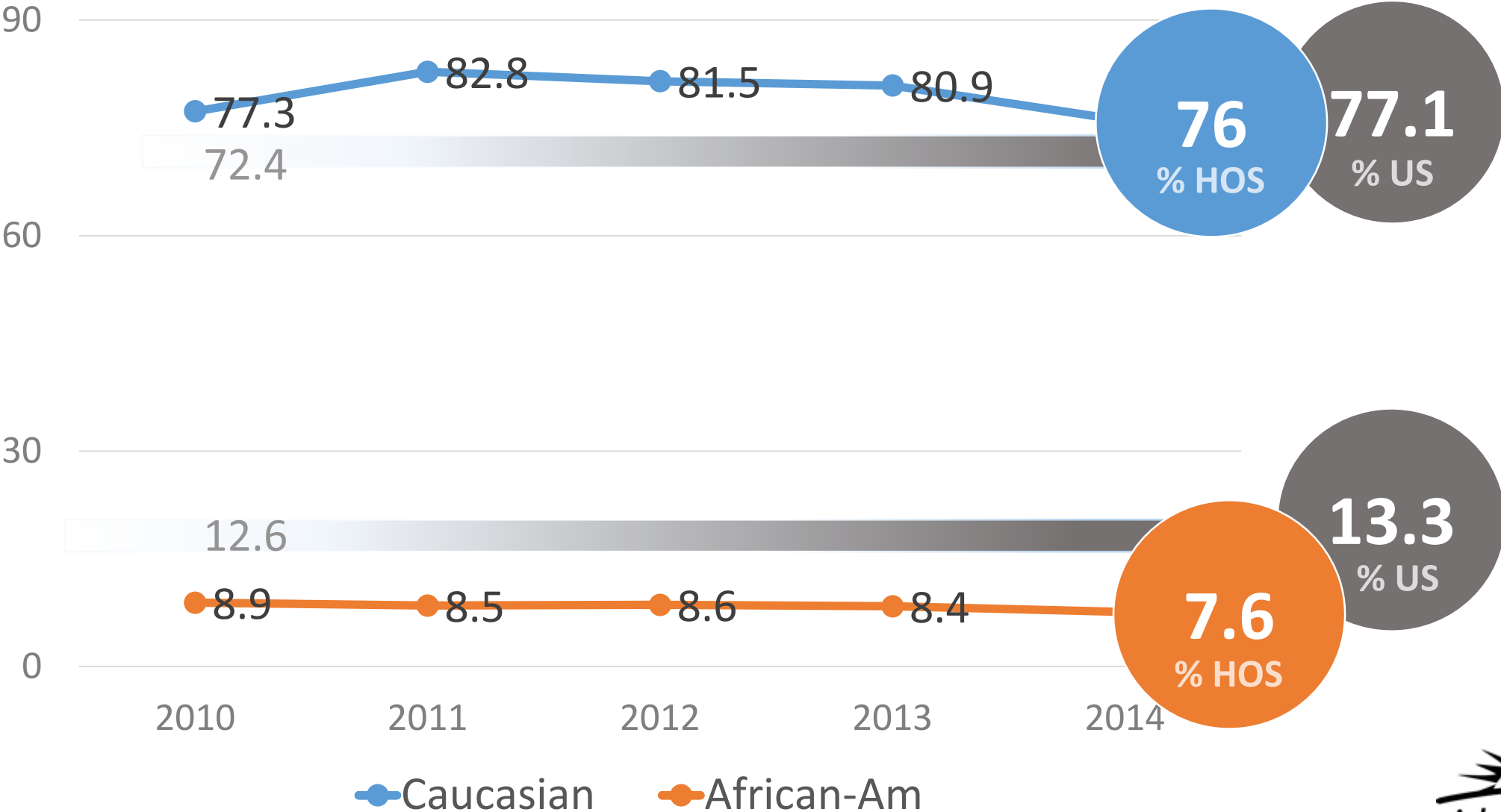
Kimberly S. Johnson, MD, MHS
Associate Professor of Medicine
Senior Fellow, Center for Study of Aging
and Human Development



How underserved nationally?

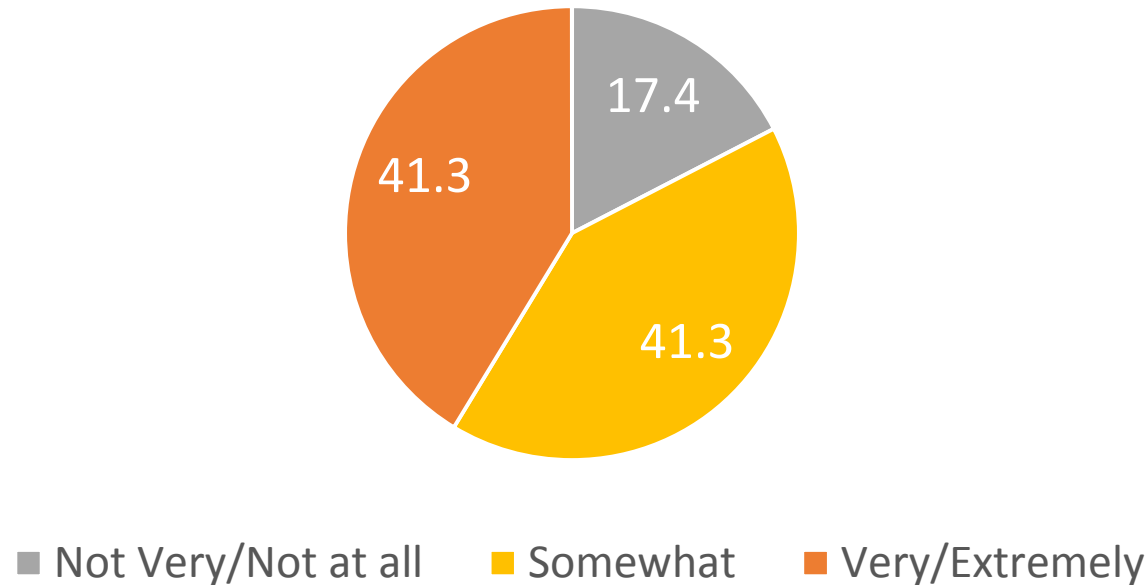
Unlike other minority groups, African Americans' numbers have gone in the wrong direction since 2010.

Percent of United States Patients Served



Are hospices concerned? (Duke Study)

How concerned are you about the % of African Americans served by your hospice?



Breaking the Color Barrier: What Can We Do to Increase Access to Hospice Care for African Americans?

Kimberly S. Johnson, MD, MHS

Division of Geriatrics, Center for Aging, Duke Palliative Care, Duke University Medical Center, Durham, NC



What are hospices doing?

Duke survey results (April 2017):

- *78% are setting goals...
but only 48% are measurable or reviewed.*
- *83% have developed strategies...
but only 20% assessed if they were effective.*
- *Only 29% had participation from senior leadership.*

Breaking the Color Barrier: What Can We Do to Increase Access to Hospice Care for African Americans?

Kimberly S. Johnson, MD, MHS

Division of Geriatrics, Center for Aging, Duke Palliative Care, Duke University Medical Center, Durham, NC



“Getting started is the hardest part.”

Duke survey recommendations (April 2017):

- *Do some research. Assess your hospice’s service to African Americans, consider local demographics.*
- *Learn about the needs of your community.*
- *Gather support and form a team: senior leadership, volunteers, community leaders.*
- *Set measurable goals.*
- *Develop a strategy to accomplish those goals.*
- *Measure the impact of your work, short & long term.*

Breaking the Color Barrier: What Can We Do to Increase Access to Hospice Care for African Americans?

Kimberly S. Johnson, MD, MHS

Division of Geriatrics, Center for Aging, Duke Palliative Care, Duke University Medical Center, Durham, NC

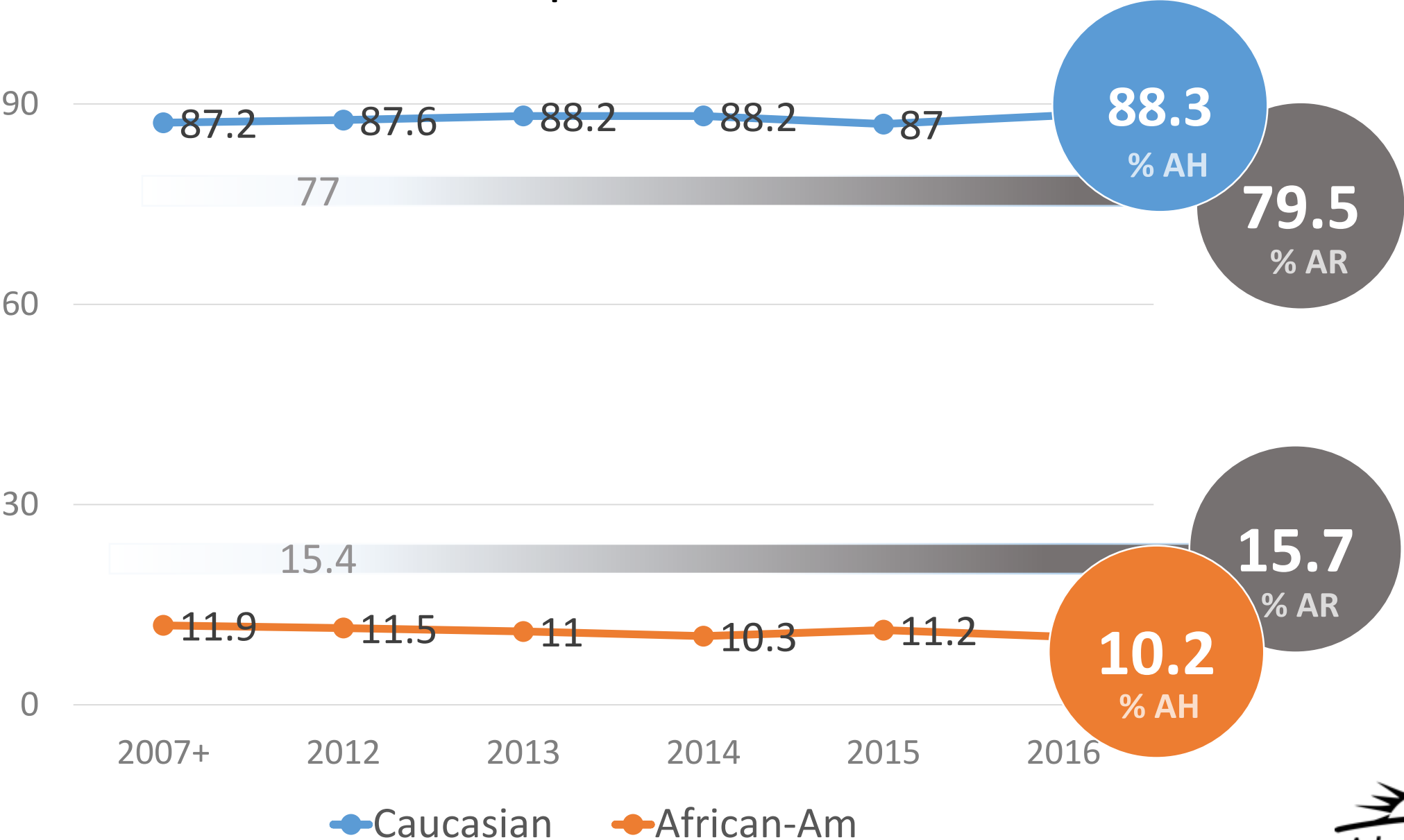


What about Arkansas Hospice?

Also low and trending in the wrong direction, our percentage of African American families is at its lowest point in 10 years.



Percent of Arkansas Hospice Patients Served



Our Strategy (begun 2015)

- Research issues & data for AH, AR, and US.
- Develop plan & propose idea to **Linda Bateman**:
 - Program buy-in critical.
 - No pilot without local program support. (No Linda, no pilot. She was our linchpin.)
- Approvals & vetting – **Judy, Dr. Allen, Donald, and Sherry Collins**.
 - Executive & management buy-in not optional.
 - **Corey** & Communications' involvement also important – a big component.
- Prospect grantors & develop proposals:
 - Local groups key – relevant, credible, trusted.
 - Perfect partners: **ARCF-PB, AR Black Hall of Fame Fdn, Ben J. Alzheimer Fdn.**
- Develop materials & relationships, coordinate releases, launch, monitor, adjust, and report.



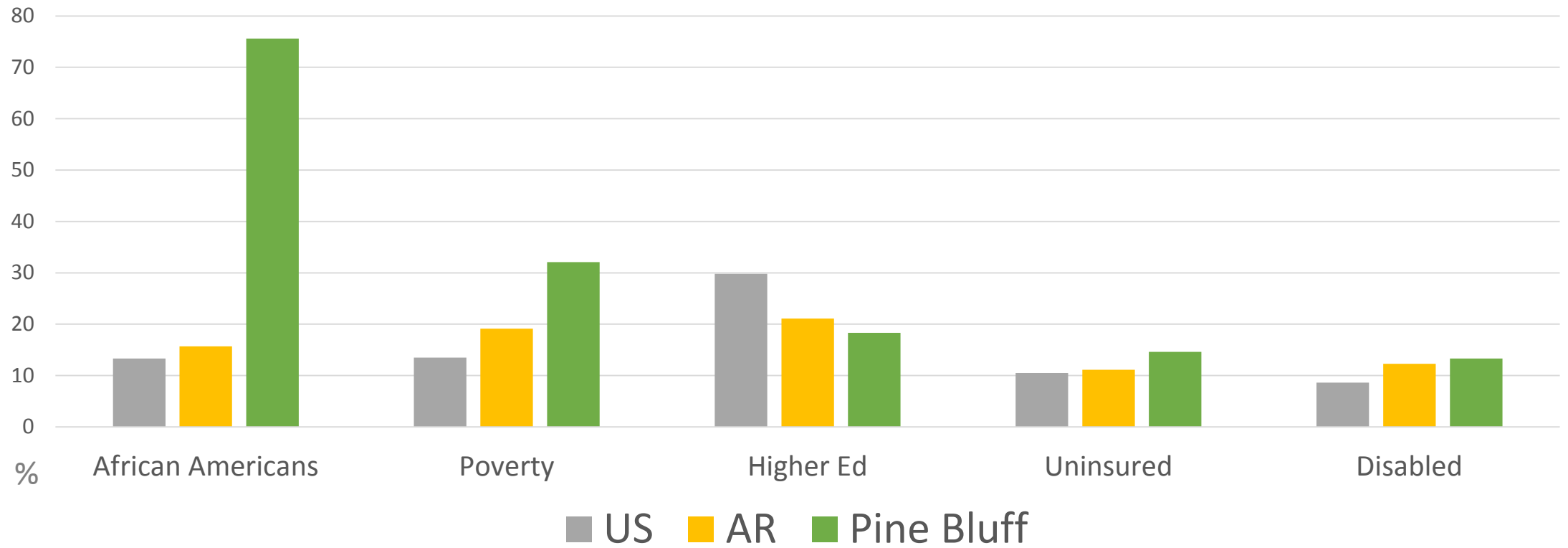
Our Plan

1. Identify pilot area.
2. Meet with staff and coordinate responsibilities and objectives.
3. Create project plan to gather information from the community, including focus groups and surveys.
4. Identify community groups, members, and leaders to participate.
5. Finalize survey, engage appropriate groups or members.
6. Inform, create, or revise outreach methods and materials.
7. Attend community and church events to build trust, learn needs, and educate about hospice services.



Why Pine Bluff?

Arkansas Hospice Mission-Relevant Vulnerabilities



Why Pine Bluff?

- Majority African American population.
- Rich cultural heritage.
- Active community and philanthropic groups.
- Active business-, educational-, and medical institutions.
- Arkansas Hospice part of the community for 12 years.
- Linda Bateman, Linda Bateman, Linda Bateman.
- John Yarbrough's program development experience in PB & Delta.



Our Survey

The survey helped me initiate conversation with African Americans about the term, “hospice.” More people I visited did not understand the term than those who did. “Hospice” meant death and death only to them. People went from being uncomfortable to comfortable having the discussion and asking questions. After the surveys and meetings, I am receiving calls from people looking for more information, saying they are more open to using hospice.

– Linda Bateman

Survey
A Little Bit About You

Arkansas Hospice Foundation
Part 1 of 4

Thank you so much for sharing your thoughts and valuable time. This short survey only takes about 5-10 minutes to complete. We don't ask your name, just a few basics to sort results. And don't worry about "right" or "wrong" answers. Our only interest is to learn more about our communities and improve our services. Rather take this survey online? Go to www.surveymonkey.com/r/onlife

1. What is your age?

☐ 18 – 24
☐ 25 – 34
☐ 35 – 44
☐ 45 – 64
☐ 65 – 74
☐ 75 or older

2. How do you identify your gender?

☐ Female
☐ Male

3. Which race/ethnicity best describes you? (Please choose only one.)

☐ American Indian or Alaskan Native
☐ Asian / Pacific Islander
☐ Black or African American
☐ Hispanic or Latino
☐ White / Caucasian
☐ Multiple Ethnicity / Other _____

4. What is your current marital status?

☐ Single, Never Married
☐ Married
☐ Living with a Partner as if Married
☐ Separated
☐ Divorced
☐ Widowed

Local Outreach by Linda Bateman

- Distributed 250 surveys and received 100. (Corey's later Facebook boost brought in over 200 more.)
- Visited groups & events, including: RSVP; Area Agency on Aging of Southeast Arkansas; Caregiver's/Alzheimer's Support Group; the Retired Teachers Association; SEARK College Resource Fair; UAPB Social Work Students; the LINKS; Circle of Friends Group; Parents from the Ivy Center for Education; Parents from Project Smile; National Association of University Women; Whispering Knoll's 2016 Resident's Care Day Event; the Jefferson County Emotional Wellness Summit, Taking Action to Build Healthier African American Communities.
- Visited many churches, including: First Presbyterian, First United Methodist Church, Mt. Calvary Baptist Church, Pilgrim Missionary Baptist Church, First Baptist Church, and Kings Highway Baptist Church.
- Personal network.



Email Outreach

- *Celebrating Diversity, Equality, and Community.*
- On the occasion of Black History Month.
- Recognizing the issue of underserved African Americans.
- Accepting responsibility for our role as a blessing to serve. This is mission.
- Pledging not just to *teach*, but to *listen*, to *learn*. Promoting the survey.



Website Outreach

- Article addresses issues and embraces our role.
- Linked to our survey and shared initial results.
- Multi-media presentation.
- Shared internally & externally.
- Audience – prospective patients & participants, but also partners and funders.
- Recognized pilot partners/funders.




From Foundation site, go to:

Learn/Our Purpose/Underserved Communities



Magazine Article

- A “special publication” of the Arkansas Times.
- Focused on minority populations where there are higher rates of:
 - Food deserts
 - Life-threatening diseases
 - Social distress & challenges
- Our article was double-sized & dual language.
- Great job, Communications Team.



The Hospice Option
BY KAT ROBINSON

Did you know that hospice care is an option for patients facing serious illness or end-of-life decisions? That specialized care, aimed at providing comfort while allowing a patient to retain their dignity, is available to anyone on Medicaid, Medicare, and most private insurances.

There's a conception that hospice care only happens in hospice care facilities. However, about 60 percent of all hospice patients are cared for at home or in a residential facility, places that provide the comfort of familiarity in the final days.

Going into hospice doesn't mean you give up your doctor. Instead, other team members are added to your care, including a chaplain, social worker, nurse, certified nursing assistant and other professionals who excel in end-of-life care.

Hospice care is not reserved for the elderly. It's an end-of-life service for anyone. Arkansas Hospice, a community-based not-for-profit organization, even has a pediatric unit to assist children and their families.

That care doesn't end after a patient's death. Bereavement services are made available to patient families and any member of the community for a minimum of 13 months after the patient has passed away.

A recent study by the Icahn School of Medicine at Mt. Sinai shows higher quality services and better outcomes for patients and family with hospice.

If you would like more information on hospice care, contact Arkansas Hospice at (877) 713-2348 or by visiting arkansashospice.org.

ARKANSAS Flavor
DELICIOUS & NUTRITIOUS DISHES ON A BUDGET
PLATILLOS DELICIOSOS Y NUTRITIVOS ECONOMICOS
50
SMART SNACKS FOR KIDS
RECEITAS INTELIGENTES PARA NIÑOS



Magazine Ad

Communications also developed ads addressing two destructive myths persisting in African American communities about hospice:

1. Does *not* mean “giving up” on loved ones.
2. *Not* a place where patients are left – care is most often at patient’s home, surrounded by family, loved ones, community and church leaders...



Hospice isn't giving up...

It's helping Dad live his last days to the fullest here at home.

Arkansas Hospice helps patients and families make the most of each moment with compassionate, award-winning care.

  www.arkansashospice.org ♦ Toll-free: 877-713-2348



Arkansas Hospice

Radio Ads


- Aired on stations popular in the local community.
- Aired four months in 2015 & 2016, including the holiday season.
- Spoke directly to common misconceptions:
 - Not a place to die, can stay at home with all loved ones
 - Covered by Medicare, Medicaid, VA, private insurance



Social Media

Arkansas Hospice
Published by Scott Christian [?] · May 4 at 7:33pm ·

Tanika Nabrit regrets that she didn't learn about hospice services sooner for her mother, who died peacefully at home last February. Initially, though, some of her family members were skeptical about hospice care – as are many other African Americans. Ultimately, Tanika said hospice helped improve her mother's quality of life; plus, it helped Tanika deal with mother's loss. "We all love her, miss her and cherish her," Tanika said. "But her memory and legacy live on, and hospice helped get us through it."



Blacks less likely than whites to use hospice care
Tanika Nabrit had always thought hospice was a place where people went to die. Even after her mother, Josephine Bell, a bighearted woman who cared for everyone as if they were family, learned in September 2014 that she had...

DISPATCH.COM

939 people reached

Arkansas Hospice
Published by Scott Christian [?] · February 3 ·

Statistics show that many African Americans remain skeptical of hospice care. This report offers some interesting insights as to why this trend exists — as well as a look at some of the steps being taken to help around.



A Matter Of Faith And Trust: Why African-Americans Don't Use Hospice
Even as end-of-life planning gains favor with more Americans, African-Americans, research shows, remain very skeptical of options like hospice and advance...


KHN.ORG

1,211 people reached

Boost Post

Arkansas Hospice
Published by Corey Gilmore [?] · September 15, 2015 ·

Hospice care is on the rise in the U.S., as half of white Medicare recipients enroll in hospice care before death. But black Americans are signing up in much lower numbers. HuffPost Live takes an in-depth look at why the racial divide in hospice care.



Why Don't Black Americans Trust Hospice Care? - HuffPost Live
Hospice care is on the rise in the US as half of white Medicare recipients enroll in hospice care before death. But black Americans are signing up in much lower numbers. HuffPost Live takes an in-depth look at why the racial divide in hospice care.

LIVE.HUFFINGTONPOST.COM | BY NANCY REDD

338 people reached

Boost Post

Arkansas Hospice
Published by Corey Gilmore [?] · August 31, 2015 ·

What does it mean that "African Americans and other minorities are at greater risk of not dying well," as Duke Divinity School Professor Richard Payne says? Since our mission is to provide end-of-life care to everyone absolutely equally, it means that we have work to do, because it's true: nationally and in Arkansas, hospice services to minorities are disproportionately low. Stories like this one help to illustrate the problem, raise awareness, and point toward solutions. Would you like to learn more about our work to address this problem? Or do you have something to share that would help us learn more about it? Please leave feedback or contact us today.

<http://www.nytimes.com/.../a-racial-gap-in-attitudes-toward-hospice-care>



A Racial Gap in Attitudes Toward Hospice Care
Suspensions about end-of-life options remain strong among many African-Americans. Some doctors and clergy members are going to church to reshape views.

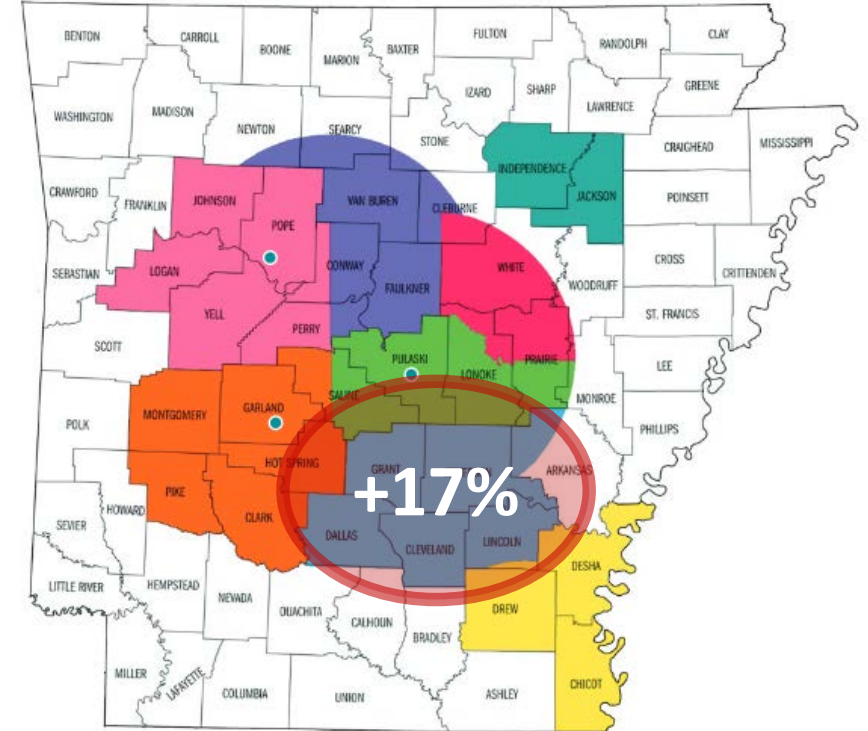
NYTIMES.COM | BY SARAH VARNEY

169 people reached

Boost Post

Did it work?

- In 2016 Arkansas Hospice dropped a full percentage point in service to African Americans, a 10-year low.
- Percentage change from 2015 was **-9%**.
- Site-by-site, percentage change from 2015 was **-26%**.
- One of the few sites with an *increase* in the percentage of African American patients served in 2016 and the largest by far was... **Pine Bluff at +17%**.

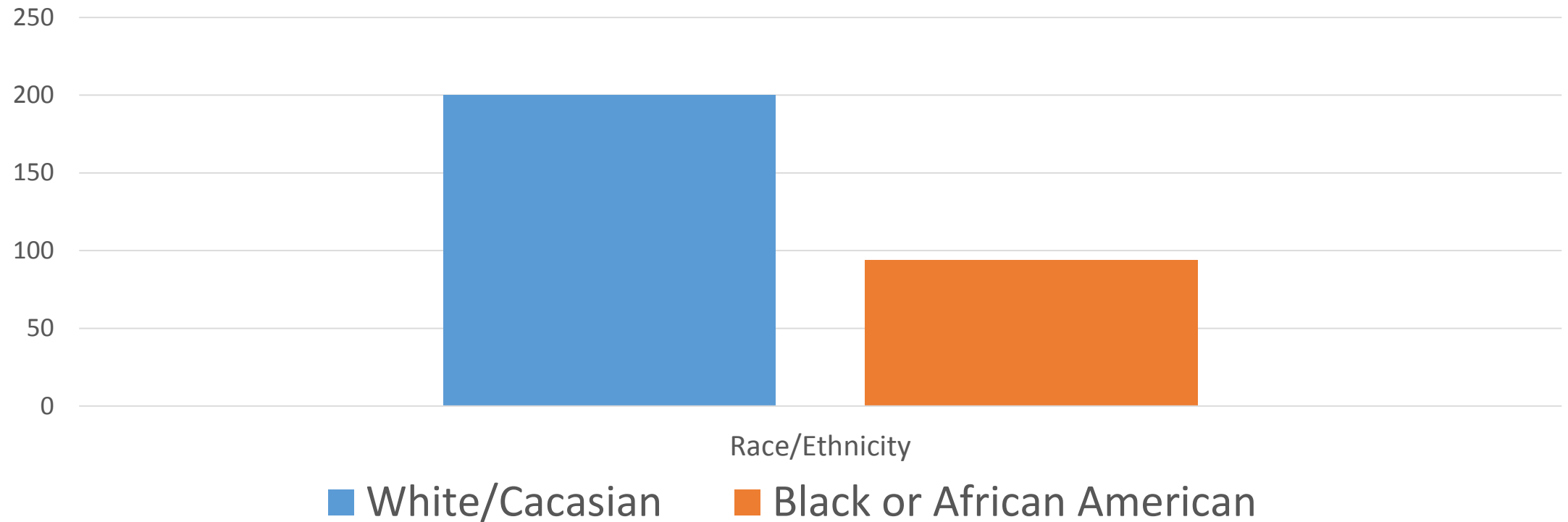


Survey Results

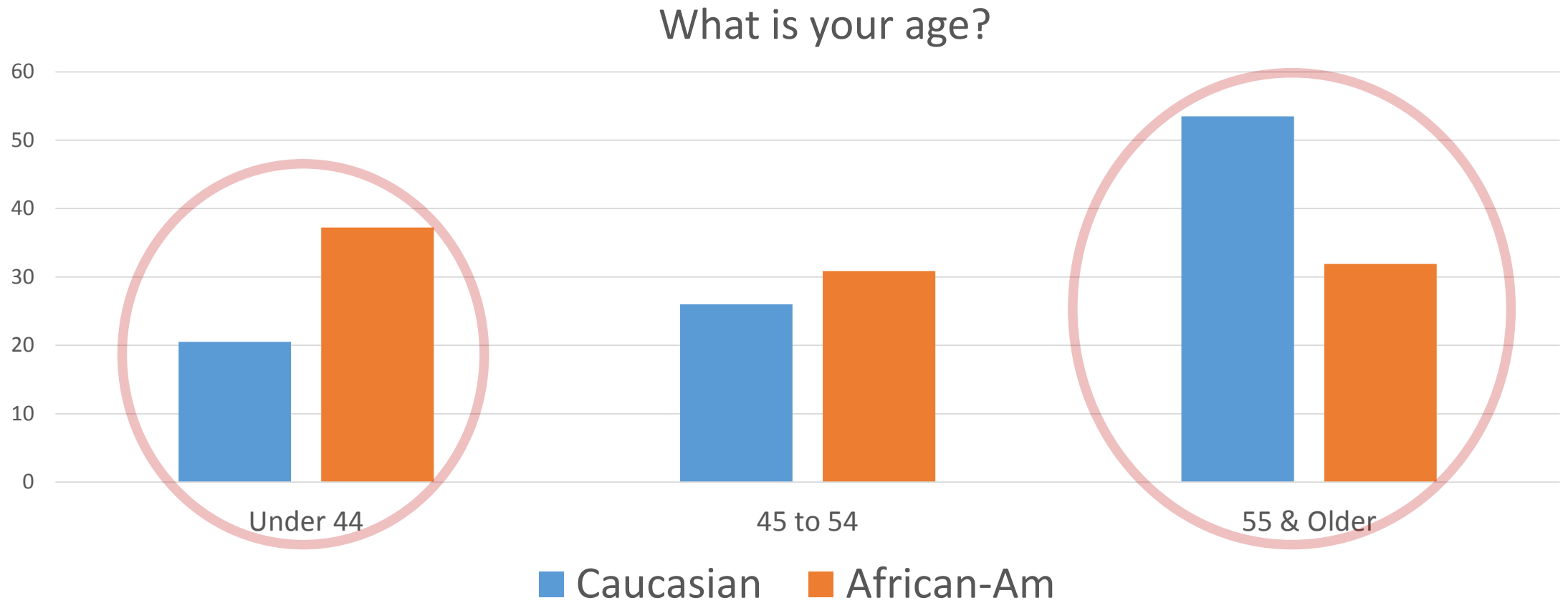
Areas of significant difference between our African American and Caucasian respondents.

Our Respondents

Which race/ethnicity best describes you?

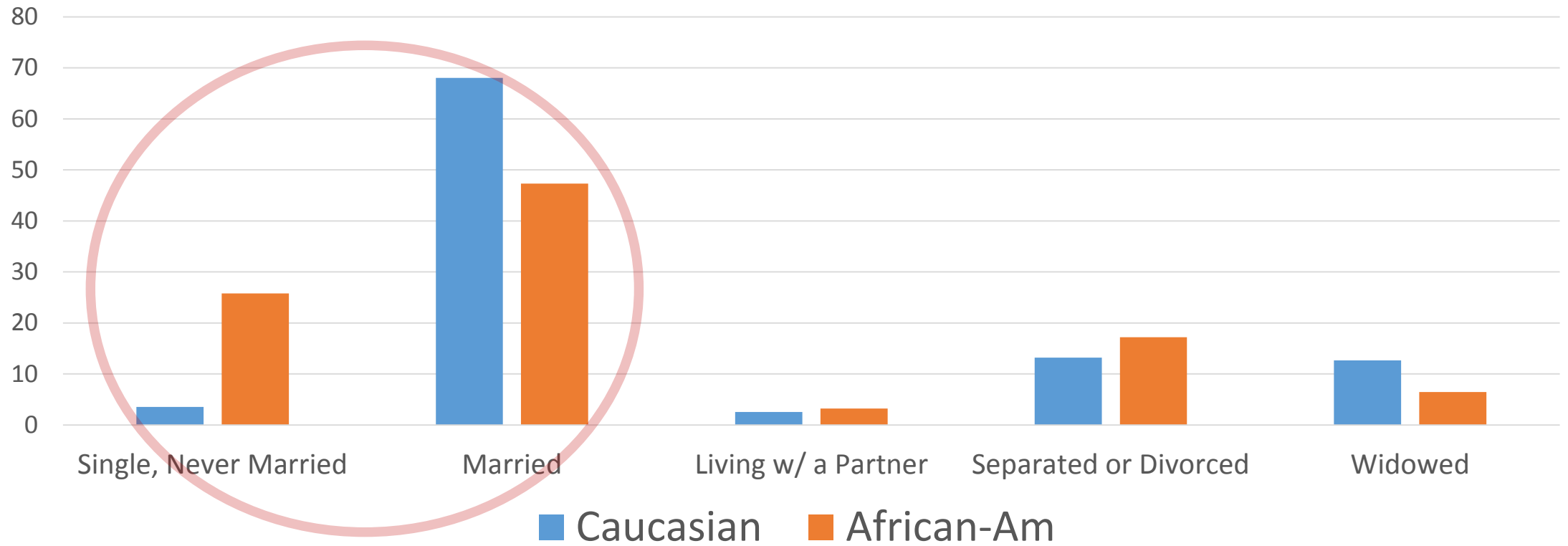


Significant Age Difference



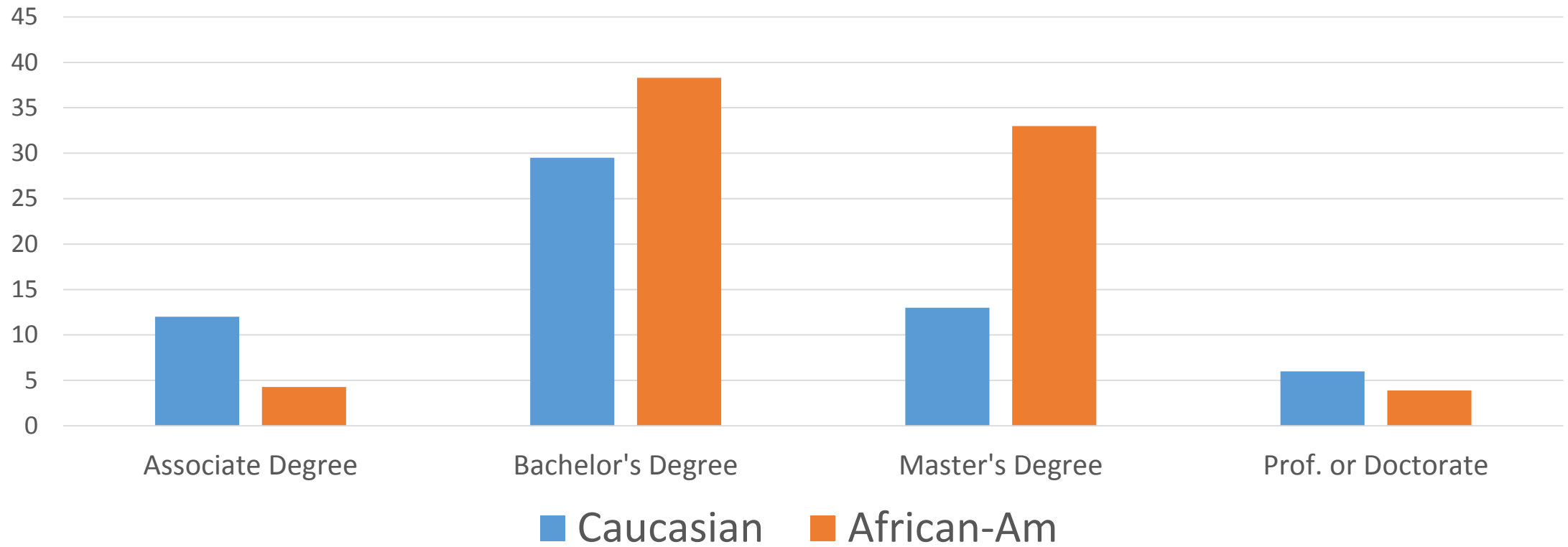
Significantly More Single African Americans

What is your current marital status?

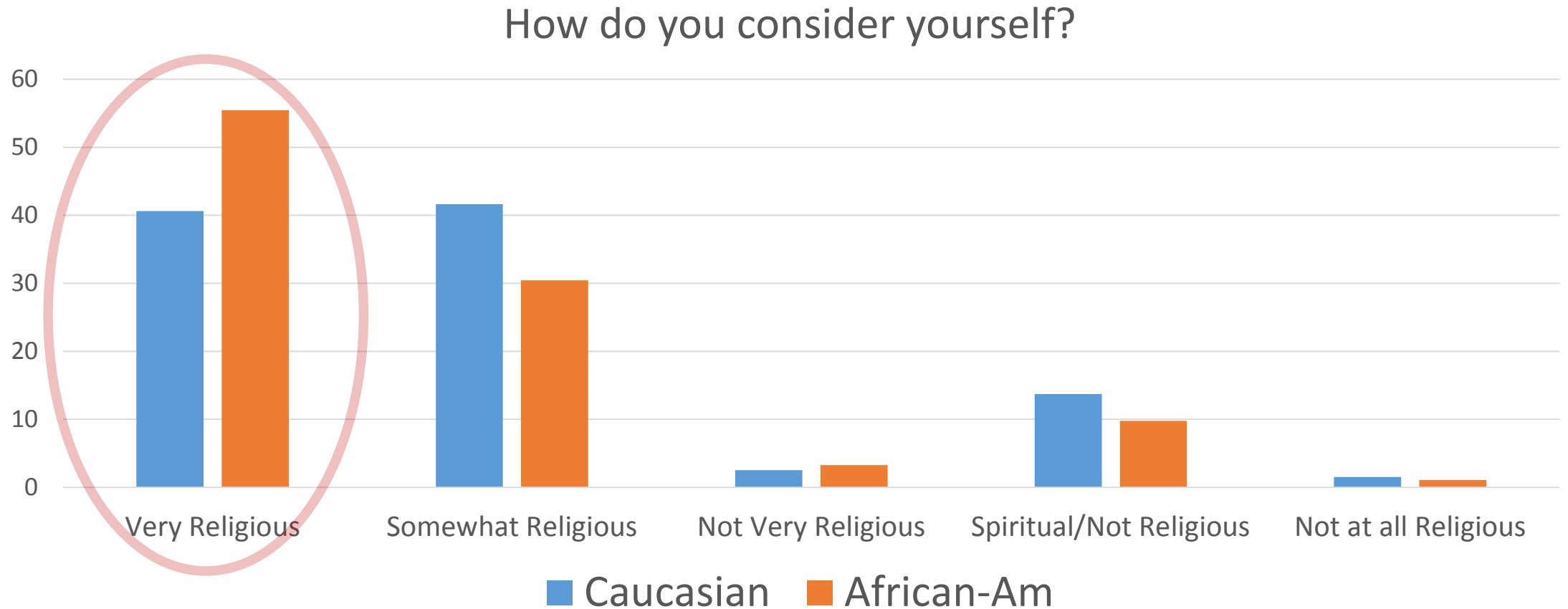


African Americans More Highly Educated

What is the highest level of education that you completed?

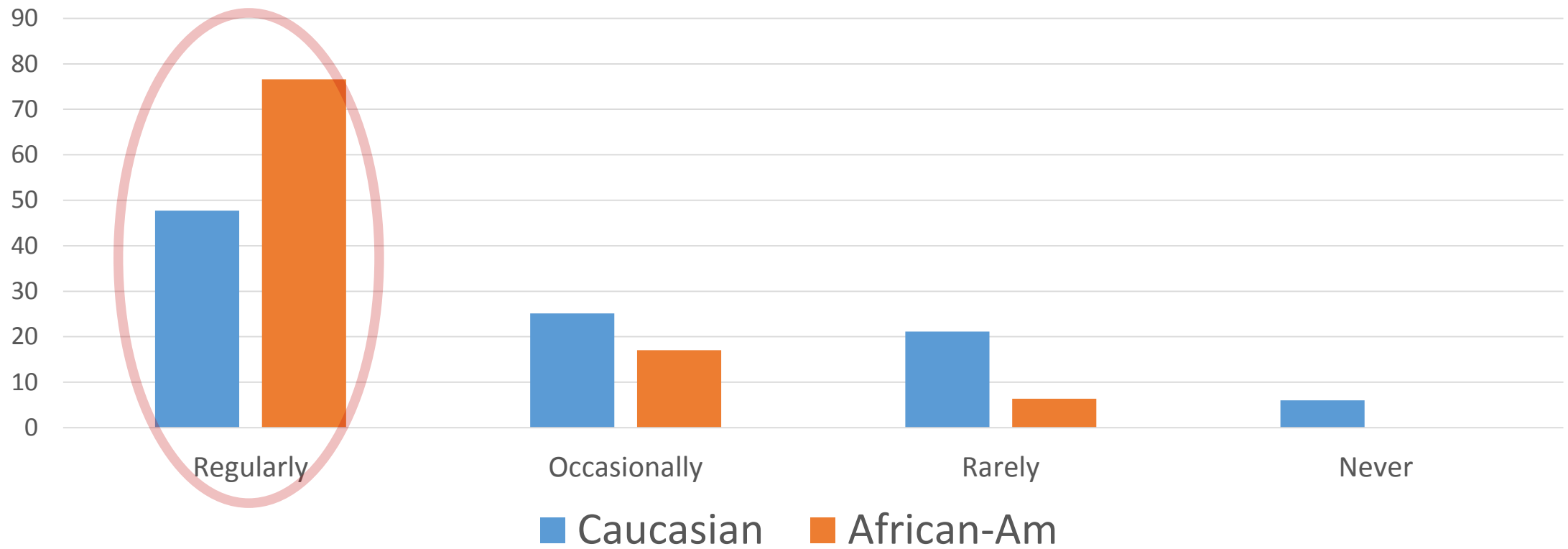


African Americans More Religious



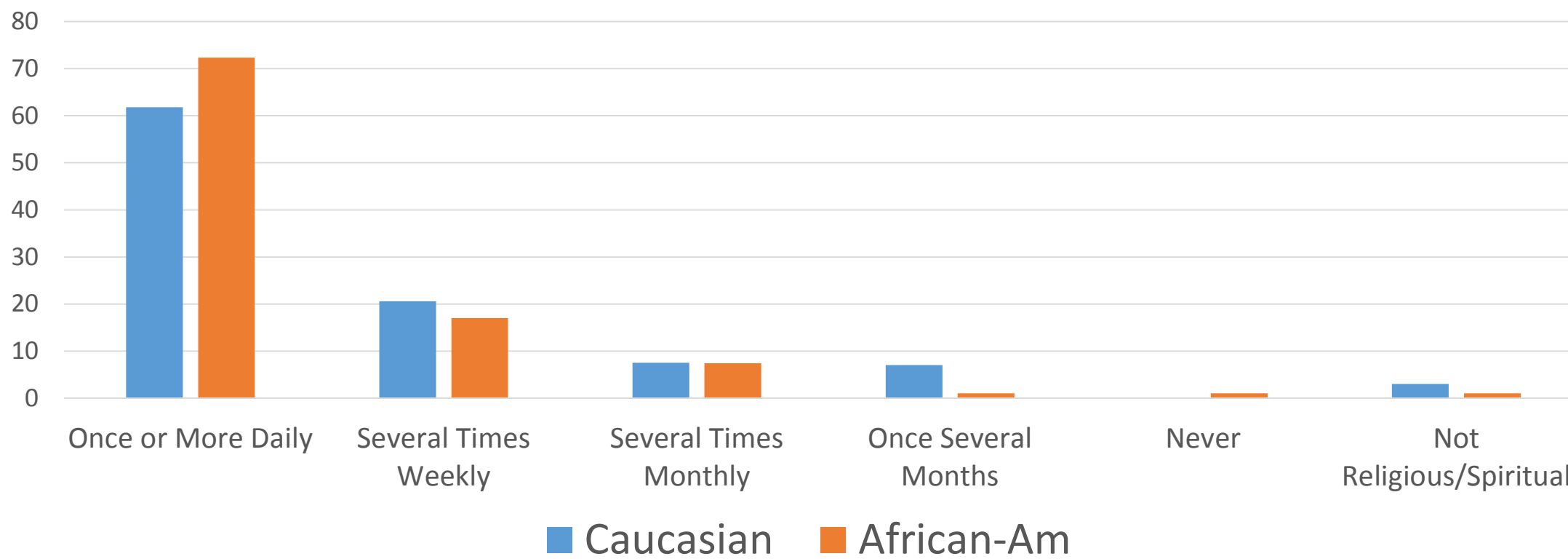
African Americans More Church-Going

How often do you attend religious or spiritual services?



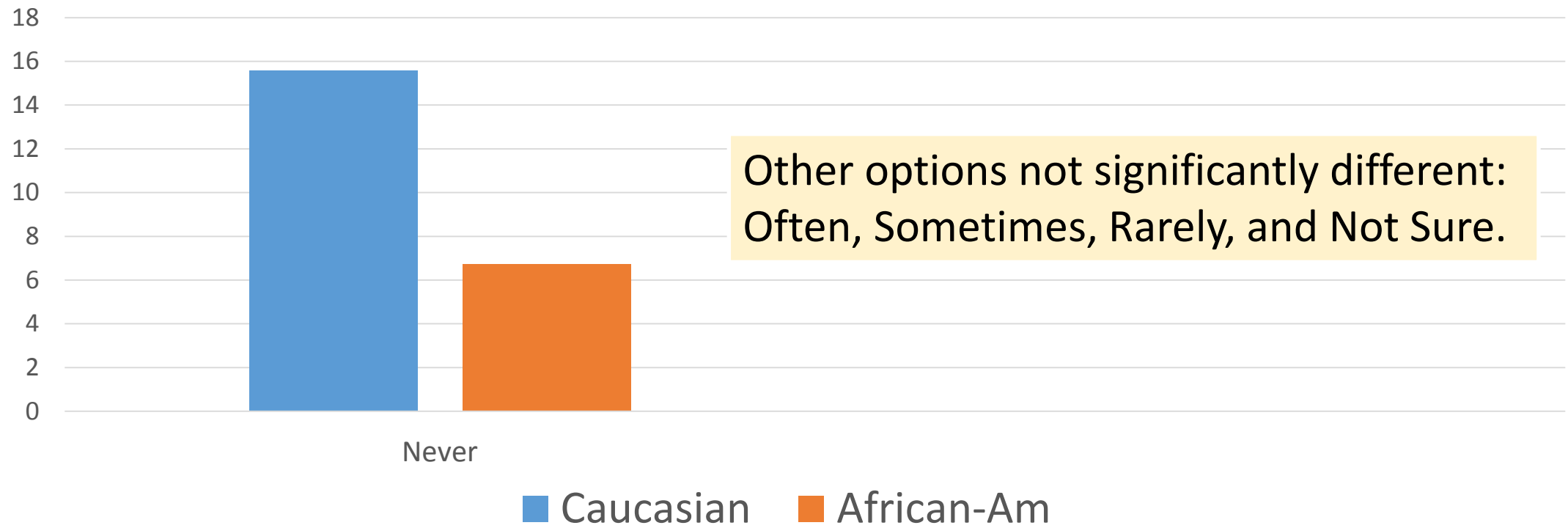
Strength from Spirituality Similar

How often do you find strength in your religion or spirituality?



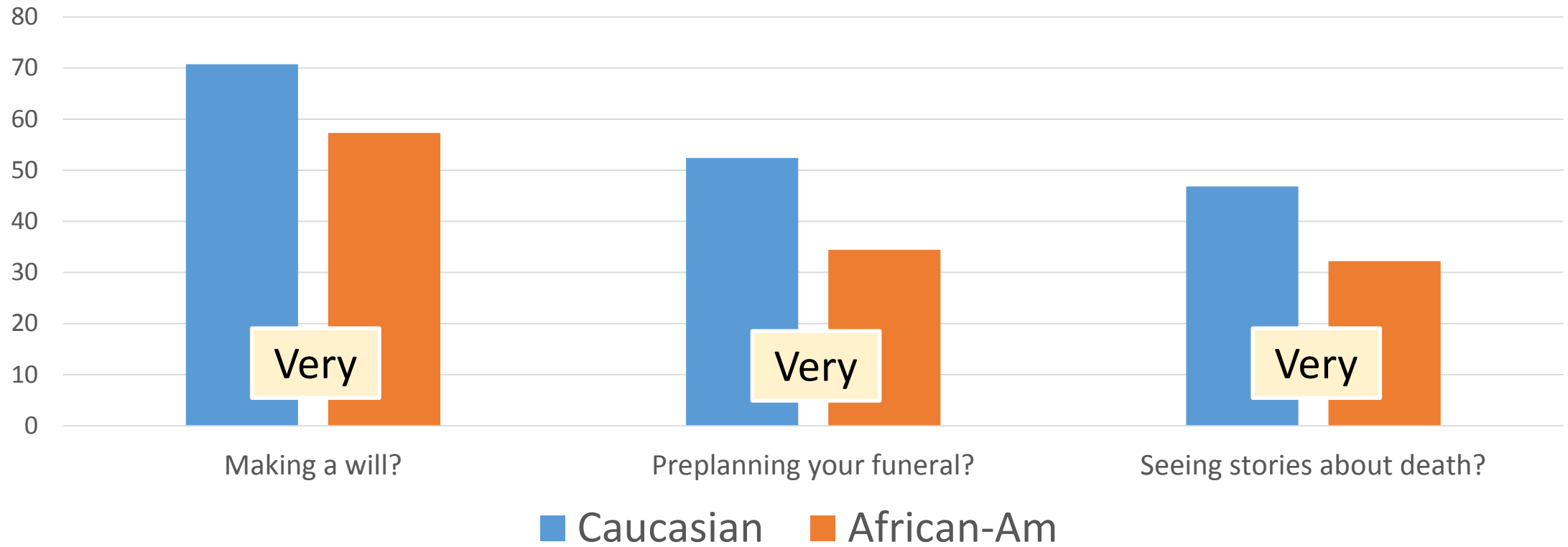
More Caucasians Never Talked about Death

Growing up, how often did your family talk about death or dying?



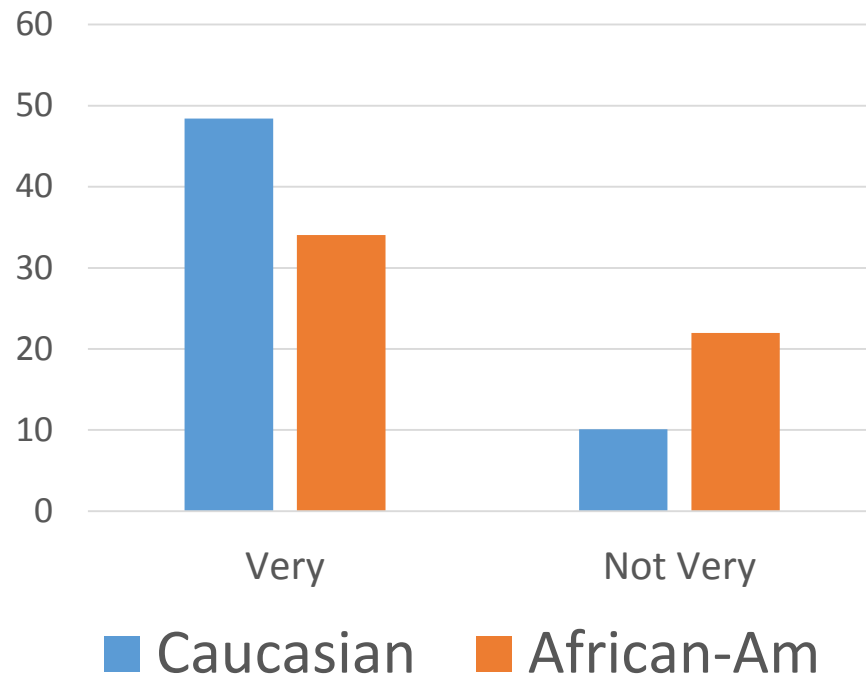
Advanced Planning Favors Caucasians

Today, how comfortable are you...

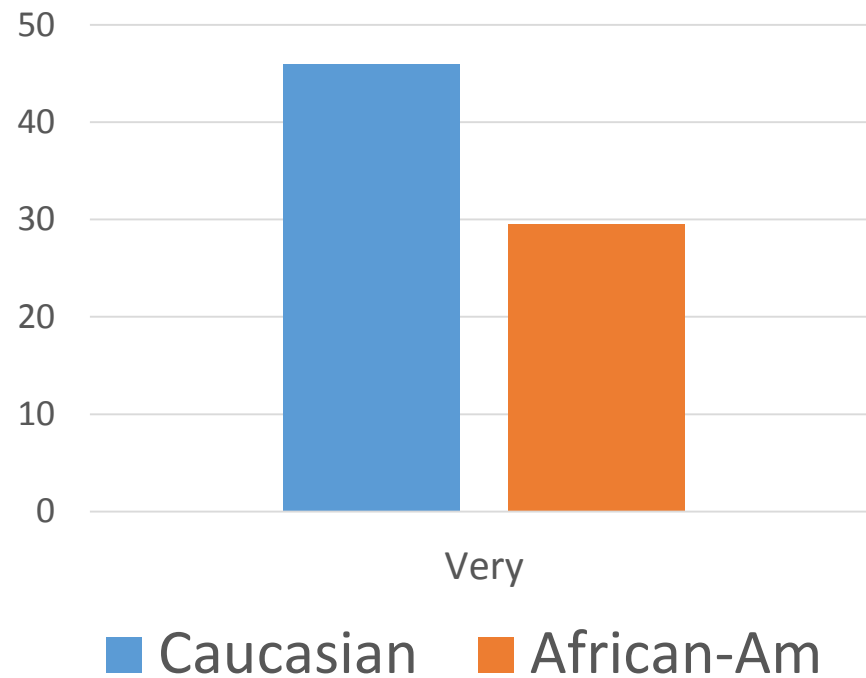


Caucasians Significantly More Confident

... that loved ones know
how you would want to be
cared for?

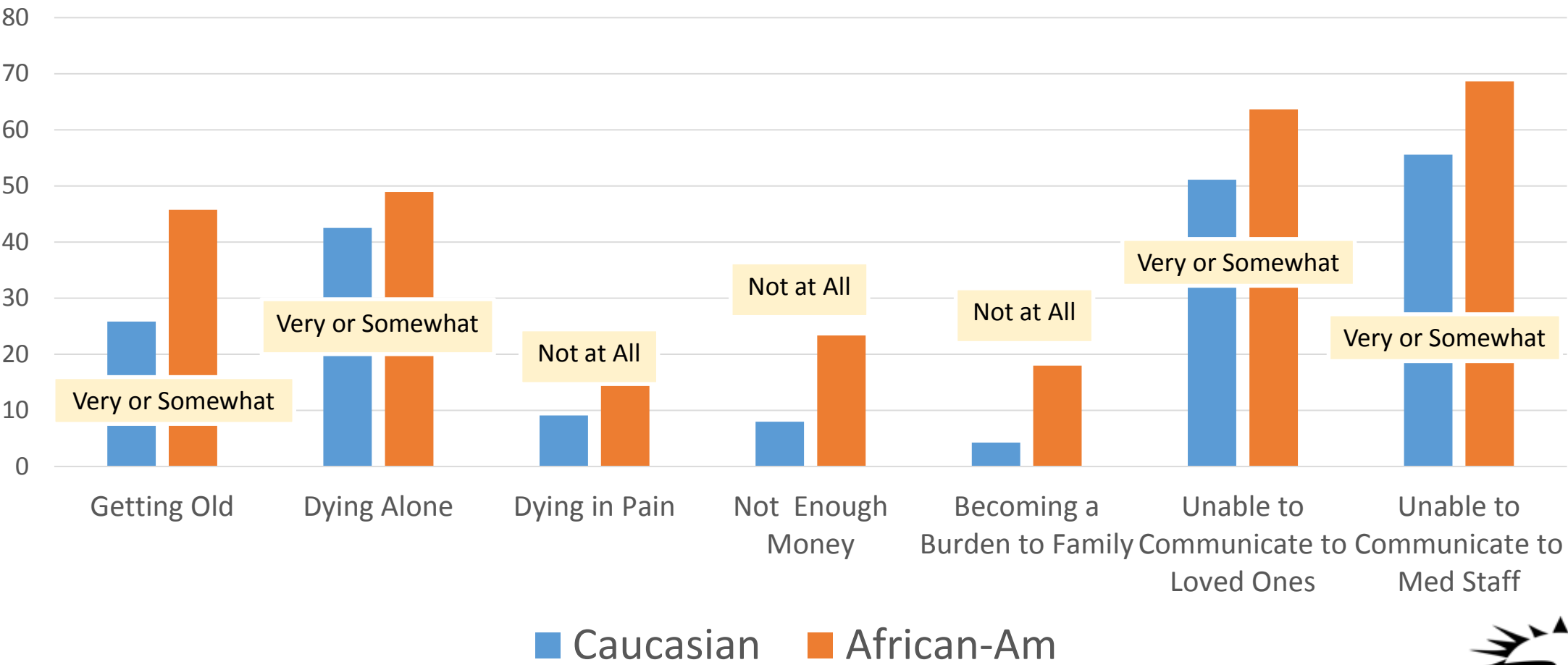


... that you know how your
loved ones would want to
be cared for?

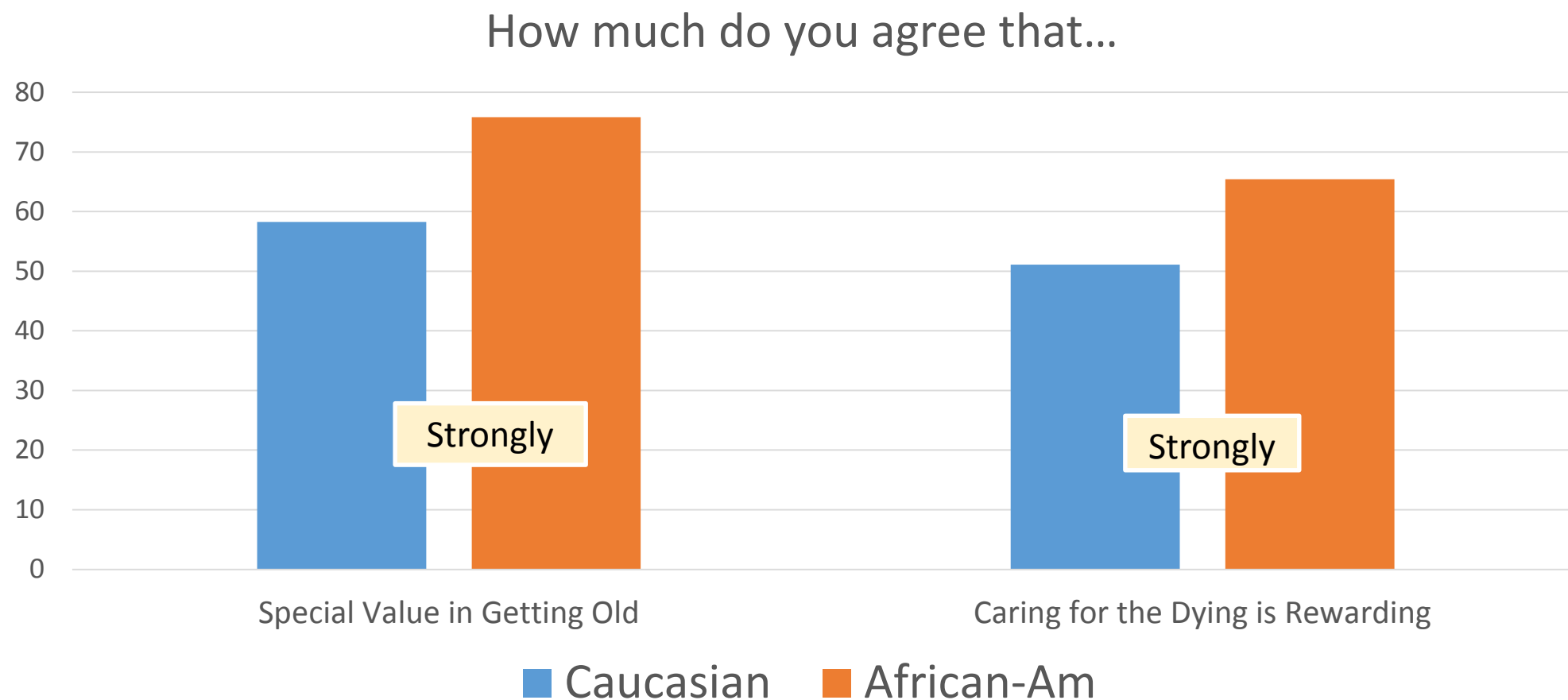


End-of-Life Fears

How afraid are you of...



Aging and Dying, Differences



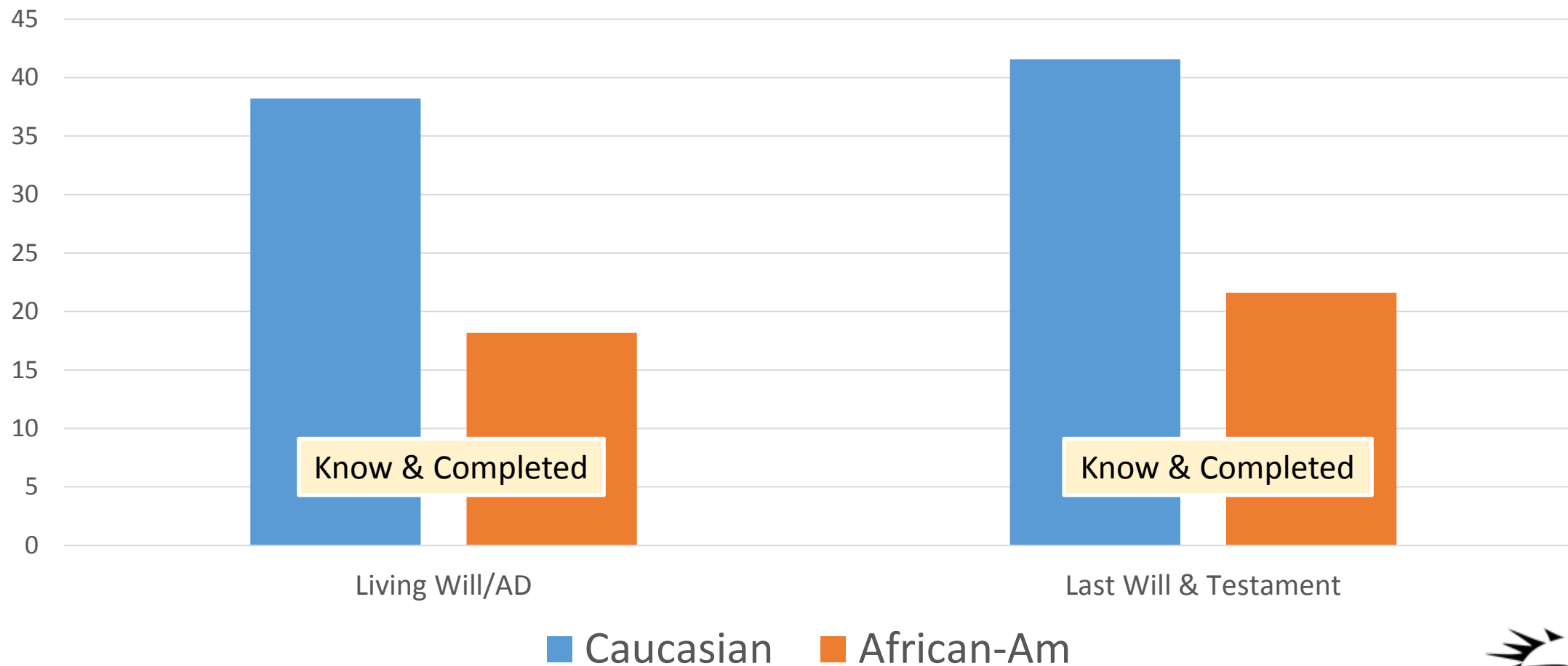
Aging and Dying, Similarities

African Americans and Caucasians are much agreed that...

- Dying is an important part of life.
- You would want to know when you're going to die.
- Making peace with yourself and loved ones before you die is important.

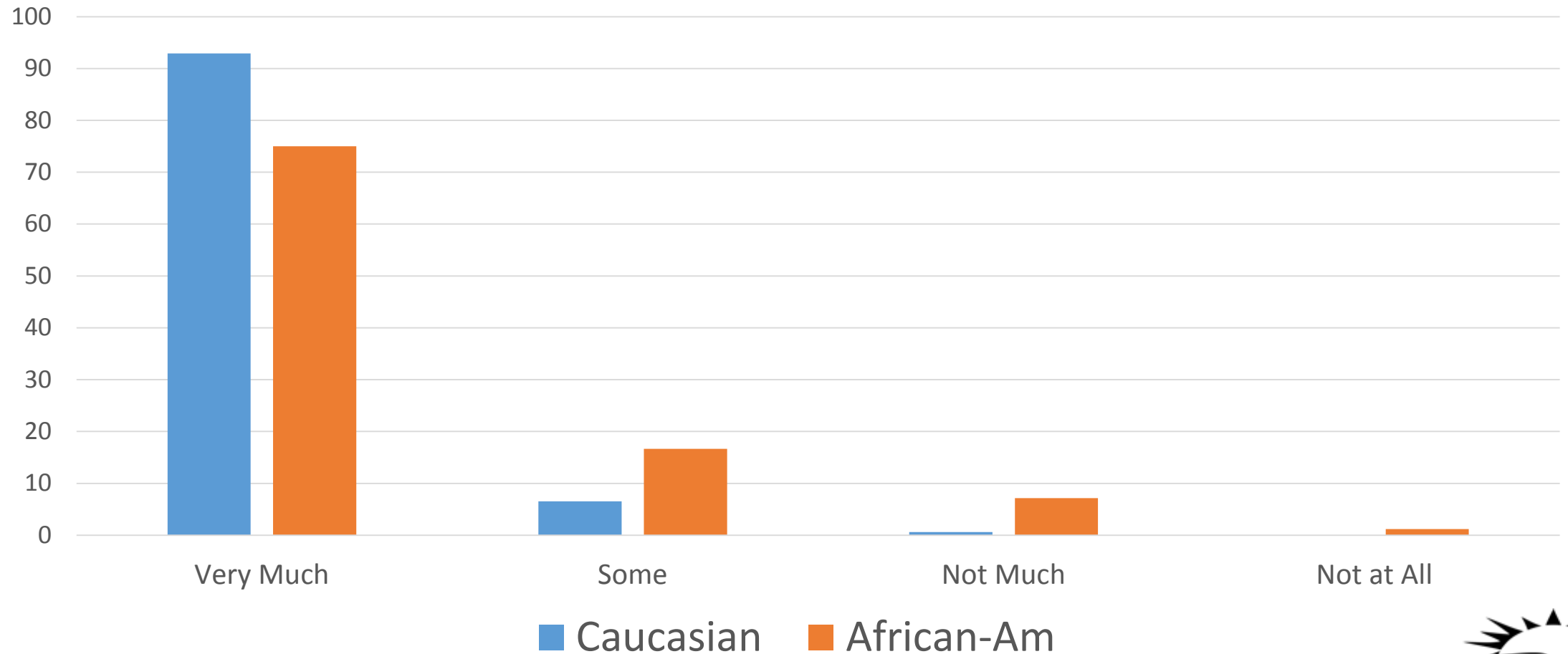
Wills and Advance Directives

How much do you know about...



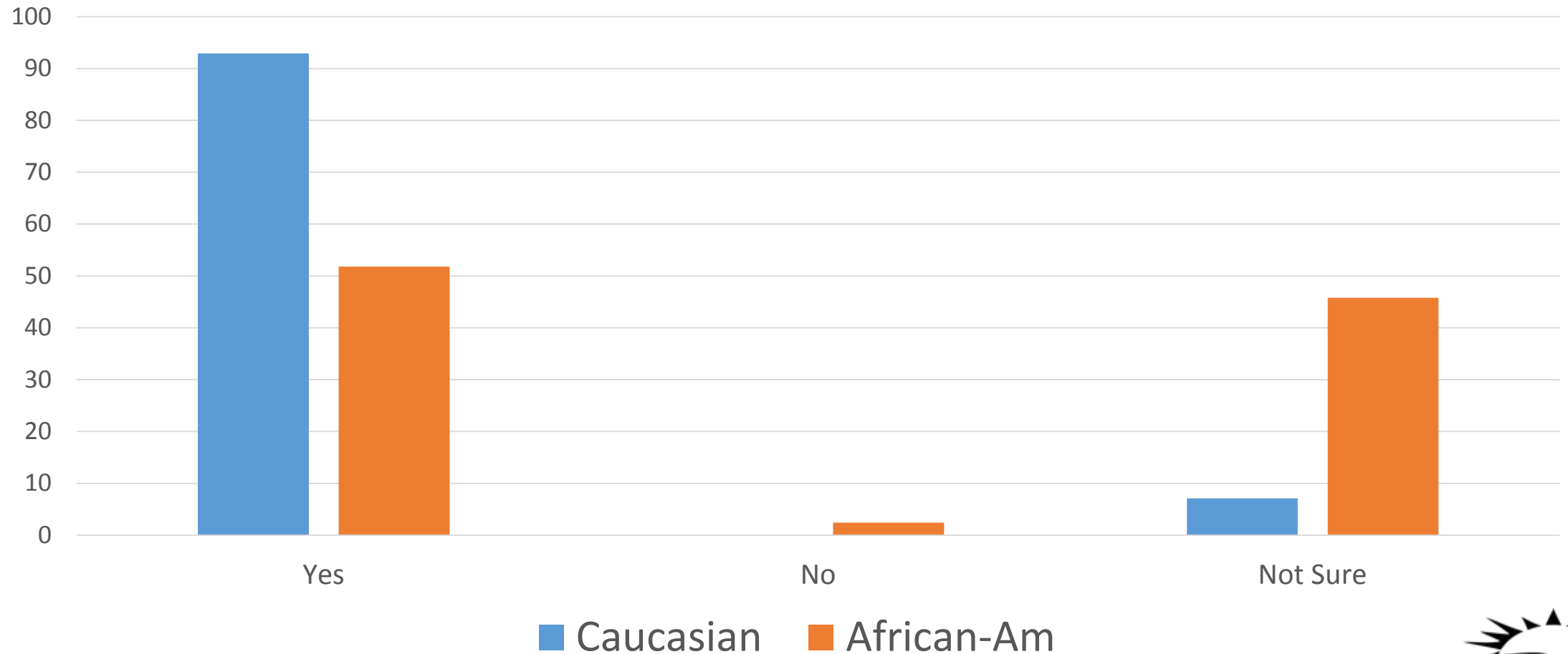
The Big One, Part 1

Have you heard of hospice services?



The Big One, Part 2

If you were dying, would you want hospice services?



Recommendations

Possible Next Steps

Recommendations

- Do research
- Evaluate data
- Get program and executive buy-in on proposal
- Create plan, assign responsibilities, and set goals
- Prospect funders and develop community partners
- Implement plan
- Report results
- Evaluate and strategize



Recommendations, Next Steps

- Continue what we started.
 - Do what works.
 - Develop toolkit.
- Expand effort:
 - Iteratively? Repeat model in next area.
 - Broadly? Assume entire service area is next goal & go for scale.
 - Funding should realize program plans.
- Train:
 - Use remaining funds to begin training with Just Communities of Arkansas.
 - Start with Leadership Team, then plan growth.
 - “If you can’t hire diversely, then train for diversity.”
- Increase staff diversity.
- Increase board diversity.



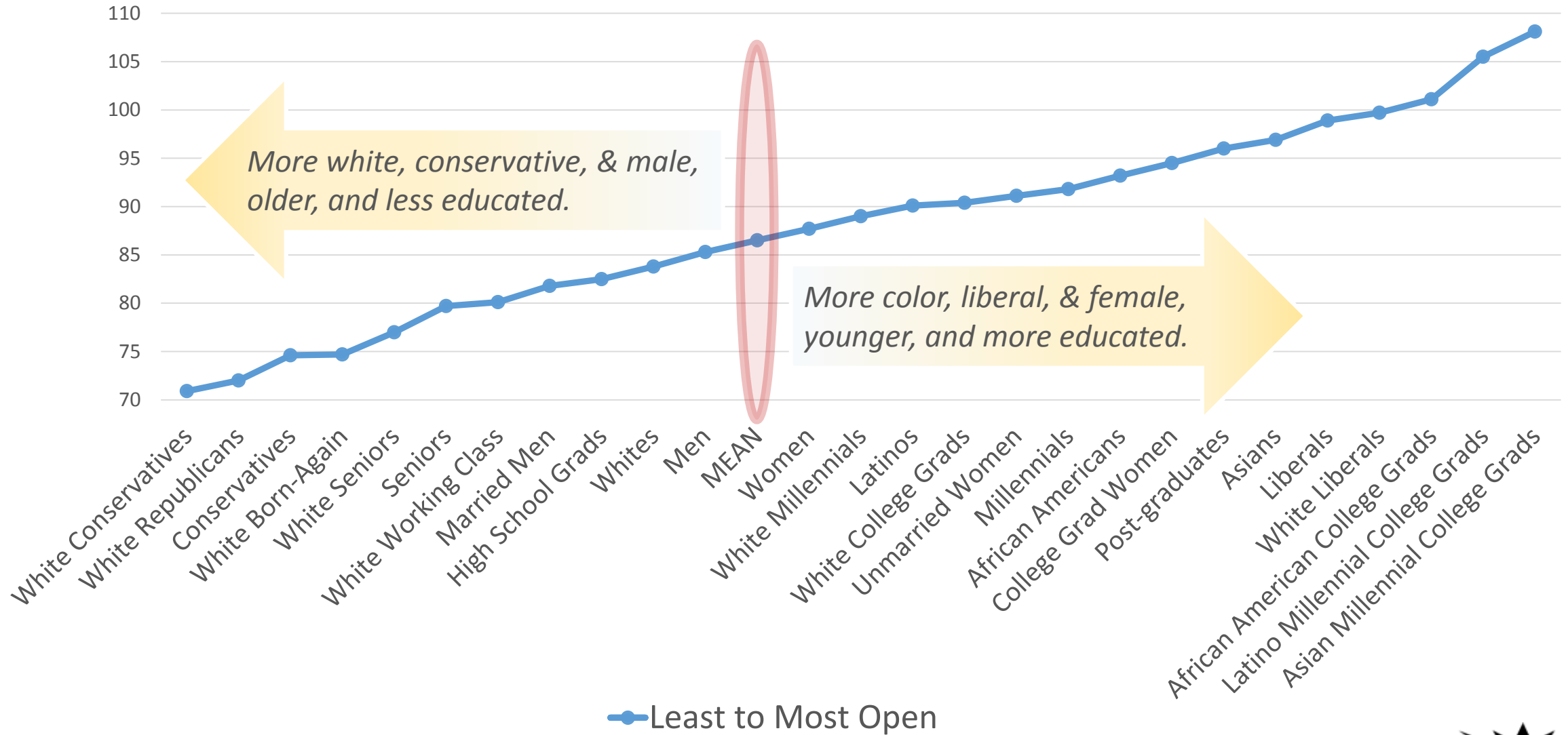
From NHPCO's *Inclusion and Access Toolbox*:
Assess, Engage, Educate, Evaluate, Repeat

Arkansas Hospice's Organizational Diversity

	% Staff	% Boards	% State	% Nation
Caucasian	74.9	93.5	79.5	77.1
African American	12.4	6.5	15.7	13.3
Asian	0.5	0	1.6	5.6
Latino	0.9	0	7.2	17.6
Unknown	11.3	0	0	0



Openness to Diversity



More Recommendations

Maintain & grow partnerships, including:

- Michelle R. Smith, director of Office of Minority Health & Health Disparities
- Michael Knox, former director of Arkansas Minority Health Commission
- Donald Wood, executive director of Just Communities of Arkansas
- Arkansas Black Hall of Fame Foundation and our other funders, including Komen Arkansas
- Health Care Community and Arkansas Dept. of Health
- Area Agencies, Community Organizations, Churches, etc.
- Many Regional, National, & Governmental Organizations



Michelle R. Smith, PhD, MPH



Thank You

Linda Bateman & Sherry Collins in Pine Bluff

Judy, Andy, and Donald

Dan Marchetti

Corey, Scott, and Tim

Our Boards

Our Funders

Our Community Partners

Our Survey Respondents

Most importantly, our patients and their loved ones and our staff who serve them every day. Specific thanks to our African American patients and families.

We recognize that social justice doesn't just happen, and it's not just our responsibility, it's our privilege to serve the cause. It's our mission.

