Black Religion, Cancer Patients, and Bioethics Basics

Terri Laws, PhD, MDiv
13th Annual Health Disparities Workshop
Houston, Texas
June 25, 2015
Objective of the Presentation

- Introduce concepts in interdisciplinary research that frame the interrelationship between religion, cancer patients, and African American clinical trial participation

- Identify innovative ways that health professionals can work with African American religious communities related to improve clinical trial awareness and participation
Research Aim

- Aim of the research is to contribute to literature and efforts to reduce health disparities through clinical trial inclusion and participation. Multi-disciplinary, theoretically and methodologically.

- Focused theory and method – social scientific approaches to the study of religion

- Focus population: African Americans
Assumptions

- Race is socially constructed
- Religious content in emphasis and expression are socio–culturally contextual
- “Structure” or modes of interpersonal interaction and engagement culturally contextual and impact decision making
Theoretical approaches to race and racial difference

- Essentialism – inherent or innate nature of racial difference; fixed.

- Social construction – nature of racial difference counters [essentialism by theorizing that] categories are artificial or ‘man-made’ through a process of ‘social construction.’ Attributes and persons in the race category are changeable not fixed.

- Cultural approach to race meanings
Cultural approach: What does it mean when either of them asks for pain medication?

Trayvon Martin

Mark Zuckerberg
Health Disparities Modeling

That contribute to health disparities.

- Cultural factors are included among the models.
- Religion (meaning making systems) fit within cultural factors:
  - Can provide patients comfort (coping) during the stress of a cancer diagnosis
  - Can impact agency ambiguously; that is affirmatively (inclusive), declination, or avoidance of treatment decisions including clinical trial participation
Model of Health Disparities Factors

King and Williams, 1995
Race, Religion, Cultural Competence, and Bioethics

- U.S.P.H.S. Study of Untreated Syphilis in the Negro Male (AKA “Tuskegee”)

- One of the foundational cases in the development and teaching of bioethics

- A matter of black suffering – one category of address in spirituality/religion
Race, Religion, Cultural Competence, and Bioethics

- Actual facts of Tuskegee are often unknown
- Tuskegee’s contribution beyond its egregious ethical history is virtually unknown outside the specialist community and is not always interpreted for its foundational contribution
- Research on the ongoing effects of Tuskegee continues
- The cultural effects are undisputed: for too many African Americans (and other populations), Tuskegee is a metaphor representing distrust of the healthcare system and research enterprise
Other effects are often missing from the Tuskegee/suffering metaphor

  - Establishes basic *respect for persons* established *The Belmont Report*, 1979
  - Establishes informed consent
  - Helps to establish “vulnerable population”

Strips spirituality of its agency and comfort – the documented benefit of black spirituality in health
Health and bioethics literature about religious African Americans features key trajectories:

- Cancer fatalism

- End of life – greater use of resources (many are unwilling to remove supportive technologies, want ‘heroic’ measures such as life support and resuscitation during a code)

- Black participation on clinical trials may be a way to reduce health inequities
Race, Cultural Competence, and Bioethics

- After NIH Inclusion Requirements, entry of the literature of studies involving African Americans and clinical trials. *Willingness*, attitudinal studies

- What about behavioral studies?

- The tide is turning…
Diagnosis–related Clinical Trial Advocacy

“Amid Her Own Battle With Alzheimer’s, B. Smith Wants the Black Community to Look Past Dark History with Clinical Trials to Improve Research”

Huffington Post
May 13, 2015
If you could factor components of spirituality, what might be the effects of on clinical trials that are actually offered?
Blacks are more likely to self-identify as religious as measured by regular attendance at the worship services of a religious community

Altruism
- Religion can influence affirmative participation (action, not just attitude)
- Believed to be higher among persons who participate in faith communities.

At the level of individual patient choice, religious community is an untapped resource
Roles for religious communities and religious specialists

Individual patients appear to be making clinical trial decisions with less than optimal social support from their faith communities and religious specialists

- Patients may not be sharing clinical trial options with religious leaders and faith community social networks
- Patients limited to participate with their religious community on narrow, traditional spiritual matters of their decision
- Some patients want to make integrated decisions; the best of both worlds
Facilitate new roles for religious communities and religious specialists

- Relational not transactional. Partner with clinical specialists so there is information flow into the community not just when data is needed from the community.

- Laying the groundwork for individual patients’ decisions
Recommendations: Care providers and health educators

Partnering with faith communities (institutions)...

- Acknowledge faith communities as formal and informal “knowledge communities.” Information travels.
- Aid religious communities in the work they do best:
  - Form ongoing and *ad hoc* support groups within existing health ministries
  - Locate most important meaning making symbols that reinforce current and prospective patients’ progressive, risk–acceptance decisions.
Portions of this research have been supported by Award Number RC2MD004764 from the National Center on Minority Health and Health Disparities.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National [Institute] on Minority Health and Health Disparities or the National Institutes of Health.
Thank You
Questions?
EXPLORING LATINO/A CHARACTERIZATIONS AND THEIR RELATIONSHIP TO BREAST CANCER SCREENING

Lucinda Nevarez, PhD, LMSW
THE TRADITIONAL CONCEPTION OF THE HISPANIC MACHO

Aggressive
Sexist
Chauvinistic
Hyper-masculine
Fighting
Arrest
Alcohol
Wishful thinking

Attributed Predominantly to Hispanics

If your husband ever finds out
you’re not “store-testing” for fresher coffee...

...if he discovers you’re
still taking chances
on getting flat, stale coffee
...w0w be unto you!
For today
there’s a sure
and certain way
to test for freshness
before you buy

The Chef
does everything
but cook
- that’s what
wives are for!

I’m giving my wife a
Kenwood Chef
“You know, back in my days, they’d use Bayer aspirin for contraceptives. The gals put it between their knees, and it wasn’t that costly.”
"What does that make her? It makes her a slut, right? It makes her a prostitute. She wants to be paid to have sex. She's having so much sex she can't afford contraception. She wants you and me and the taxpayers to pay her to have sex."

"If we are going to pay for your contraceptives, thus pay for you to have sex, we want something for it, and I'll tell you what it is: We want you to post the videos online so we can all watch."
An Alternate View of the Hispanic Macho

Chivalrous
Emotionally Connected
Nurturing
Family Centered
Identifies with ethnic background
Problem Solving
Perspective
Respectful of Group Orientation

Opportunities for improvement in screening and adherence among women through their partners

“being responsible and providing for one’s family are critical in defining one’s manhood”
“Both in the United States and in Mexico, machismo, despite all its faults, has been part of a whole complex of impulses leading toward a more perfect realization of the potentialities of man.”

Americo Paredes

The United States, Mexico, and “Machismo”
REFERENCES


THANK YOU

Dr. Thankam Sunil
The University of Texas San Antonio

Dr. Thelma Hurd
The University of Texas Health Science Center at San Antonio

Dr. Lovell Jones
and
The Dorothy I. Height Center for Health Equity and Evaluation Research