

# **Ethno-Cultural Disparities in Palliative Care: Relevance for PAD?**

**Jeffrey T. Berger M.D.**

**Chief, Division of Palliative Medicine and Bioethics  
NYU-Winthrop Hospital, Mineola, N.Y.**

**Professor of Medicine,  
Stony Brook University School of Medicine, Stony Brook, N.Y.**

# PAD Demographic Differences

		Statewide	PAD Decedents
<b>Oregon</b>			
	White	87%	96%
	College	31%	50%
<b>Washington</b>			
	White	80%	98%
	College	34%	74%
<b>California</b>			
	White	73%	90%
	College	32%	58%
<b>Vermont</b>			
	White	94%	?
<b>Colorado</b>			
	White	88%	?
<b>U.S (non-Hispanic)</b>	<b>White</b>	<b>63%</b>	

# Disparities and Distrust in Health System

- Scientific racism 19<sup>th</sup>, 20<sup>th</sup> centuries
- Racism in research 18<sup>th</sup>-20<sup>th</sup> centuries
- Racially-based discriminatory practices
  - Inexplicit
  - Explicit – e.g. sterilization
- Reverberations
  - Organ donation – complex and confounding factors
  - HIV – conspiracy theories
  - Palliative Care
  - PAD?

Racial Bias in Health Care and Health. JAMA 2015;314(6)

Differences in attitudes toward organ donation among African Americans and whites in the United States. J Nat Med Assoc 2001 93(10)

Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? *J Acquir Immune Defic Syndr*. 2005;38:213-218.

# Disparities in Palliative Care

- Preference for more life-sustaining therapies regardless of prognosis among African Americans than whites.
- African Americans less likely to assign HCP or complete living will, in part, from suspicion of ways in which legal documents may be used against them.
- Lower utilization of Hospice Benefit
  - greater rates of revocation of hospice care.
- Knowledge about palliative care among minority older adults less vs whites.
- African Americans less likely to embrace goals of palliative care, due in particular to spiritual and religious beliefs.
- Poorer pain control; less access to pain medication.

Palliative and End-of-Life Care in the African American Community JAMA. 2000;284(19)  
Racial and Ethnic Disparities in Palliative Care Journal of Palliative Medicine. 2013 16(11)  
*Journal of Clinical Oncology* 2003 21 3

# Drivers of Disparities?

- Mistrust vs spirituality/religious beliefs?
- Health literacy vs race?
- Black/white disparities in effective communication, and in care plans when controlled for preferences
- Disparities between palliative team/hospice member and minority populations

End-of-Life Care in Black and White: Race Matters for Medical Care of Dying Patients and their Families. *J Palliative Med* 2005

Health Literacy not Race Predicts End-of-Life Care Preferences *J Palliat Med.* 2008, 11(5)

Racial Differences in Predictors of Intensive End-of-Life Care in Patients With Advanced Cancer *J Clin Onc* 27, no. 33

Racial Disparities in the Outcomes of Communication on Medical Care Received Near Death 2010; *Arch Intern Med.* 2010;170(17)

Black/white differences in attitudes toward physician-assisted suicide. *J Nat Med Assoc.* 1997 89(2)

Racial Differences in Attitudes toward Euthanasia. *J Death Dying* 2006 52 (3)

# PAD and Minority Concerns

- Studies are limited and offer unclear consensus
  - Data suggests that African Americans' higher levels of distrust of medicine may not influence attitudes toward euthanasia; spiritual concerns may be more relevant.
  - Other data suggest lower support for AD is influenced by mistrust.
- Lack of clarity may relate to quality of survey

The Difference between Blacks' and Whites' Attitudes toward Voluntary Euthanasia *J Scientific Study Religion* 1998 37, 3  
Attitudes towards assisted dying are influenced by question wording and order: a survey experiment *BMC Med Ethics* 2016 17:24

# Purported Arguments against PAD

- to protect vulnerable populations from coerced AD (e.g. NYS Task Force)
- potential to stimulate greater suspicion and mistrust, leading to further disparity/inferior quality of care
  - Absent/speculative data regarding concern

*Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in “vulnerable” groups. J Med Ethics 2007.*

Should We Impose Quotas? Evaluating the “Disparate Impact” Argument against Legalization of Assisted Suicide. J Law Med Ethics 2002 30

# Is PAD Health Policy or Social Policy

- Relatively Novel Medical Paradigm particularly in U.S.
  - Imperative
    - Serve health goals of needy population
    - Attend to sociocultural trends towards control over self
    - Other phenomenon?



# Social Policy

**“Social policies are concerned with the right ordering of the network of relationships between men and women who live together in societies, or with the principles which should govern the activities of individuals and groups so far as they affect the lives and interests of other people”**

Macbeath G., 'Can Social Policies be Rationally Tested?', Hobhouse Memorial Trust lecture, Oxford University Press, 1957,

# Health Policy- An Ethics Framework for Public Health

- Intent to reduce morbidity or mortality;
- data substantiate that a program will reduce morbidity or mortality;
- burdens of the program must be identified and minimized;
- program must be implemented fairly and must minimize preexisting social injustices;
- fair procedures must be used to determine which burdens are acceptable to a community.

Am J Public Health NE Kass 2001

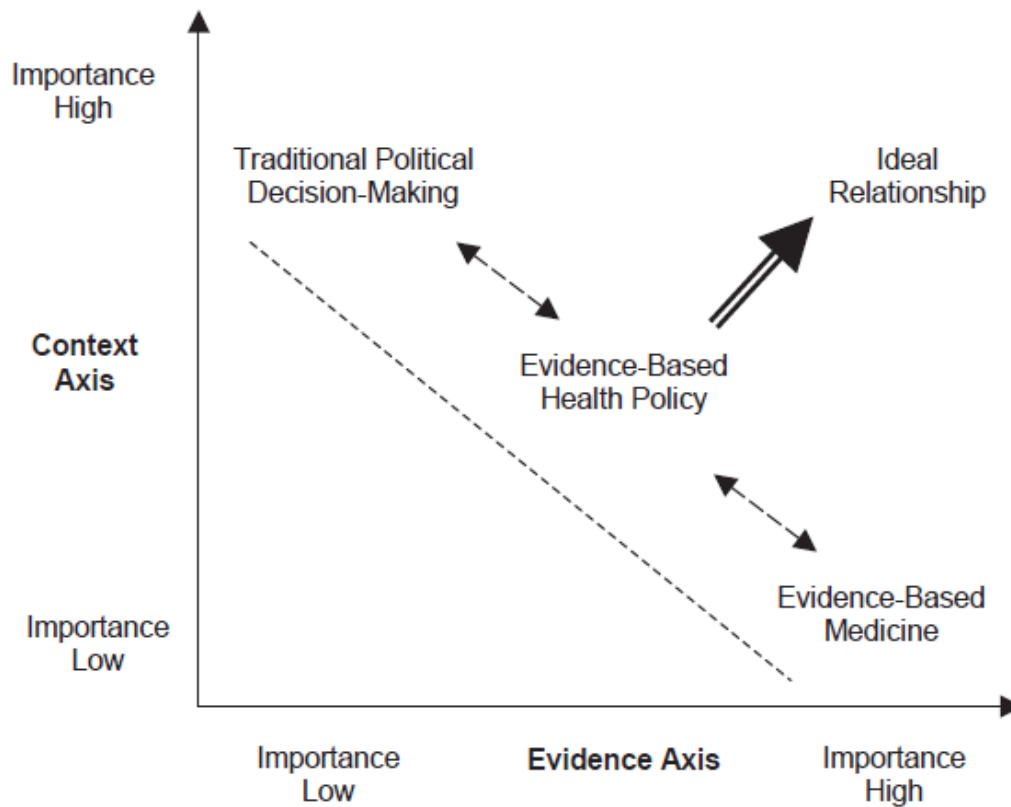


Fig. 1. Axes of evidence-based decision-making.

# Societal Implications

- What we don't know/know well:
  - Current attitudes of minority communities towards PAD
    - Factors underlying these attitudes
  - Likely influences and actual influences of PAD, if any, on:
    - Trust in physicians, health workers, hospital/system
    - Health care/system use
    - EOL care planning and preferences
    - Quality of dying
    - Hospice use
    - Organ donation activities

# Summary

- PAD is disproportionately a concern of a well-educated white demographic
- Minority populations' differences in spiritual and religious orientation, unique American socio-historical memory, and other factors may be relevant in terms of unintended consequences of legalized PAD
- To promote evidence based health and social policy, these considerations should be judiciously studied in jurisdictions in which PAD is permitted.