

# Health Literacy Not Race Predicts End-of-Life Care Preferences



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# Background

- African-Americans prefer more aggressive care at end of life\*
- Low health literacy is more prevalent in AA\*
- Health literacy may confound the relationship between race and end-of-life decision making

\* O'Brien LA, *JAMA* 1995; Blackhall LJ, *Soc Sci Med* 1999; Hopp FP, *JAGS* 2000

\* Paasche-Orlow MK, *JGIM* 2005

# Hypotheses

- Health literacy and NOT race predicts end-of-life care preferences.
- Video of dementia would overcome communication barriers due to low health literacy.

# Methodology

- **Study design**
  - Before and after interviewer-administered survey
- **Goals of care**
  - Aggressive care
  - Comfort care
- **Health Literacy**
  - REALM
    - Low  $\leq$  6<sup>th</sup> grade
    - Marginal 7-8<sup>th</sup> grade
    - Adequate  $\geq$  9<sup>th</sup> grade

# Verbal Description of Advanced Dementia

- “I am going to describe to you an illness called advanced dementia, like advanced Alzheimer’s dementia, that you may or may not be familiar with. Advanced dementia is an incurable disease of the brain in which one is not able to communicate with others. People in advanced dementia are not able to move around or walk, get out of bed independently, eat by oneself, or communicate understandably with others. People with advanced dementia often have difficulty chewing or swallowing, and require assistance with feeding oneself. Advanced dementia is an incurable disease and most commonly occurs after many years of Alzheimer’s disease or as the result of strokes. People are not able to answer any questions or tell you about themselves.”

# Video Viewed by Subjects

- Two minute digital video
- Developed and edited with 8 dementia experts
- Narrative is same

# Study Participants

- Six outpatient primary care clinics
- Inclusion criteria
  - $\geq 40$  years old
- Exclusion criteria
  - Previous relationship with a person with advanced dementia
  - Self-identified as other than AA or White
  - Non-English speaking

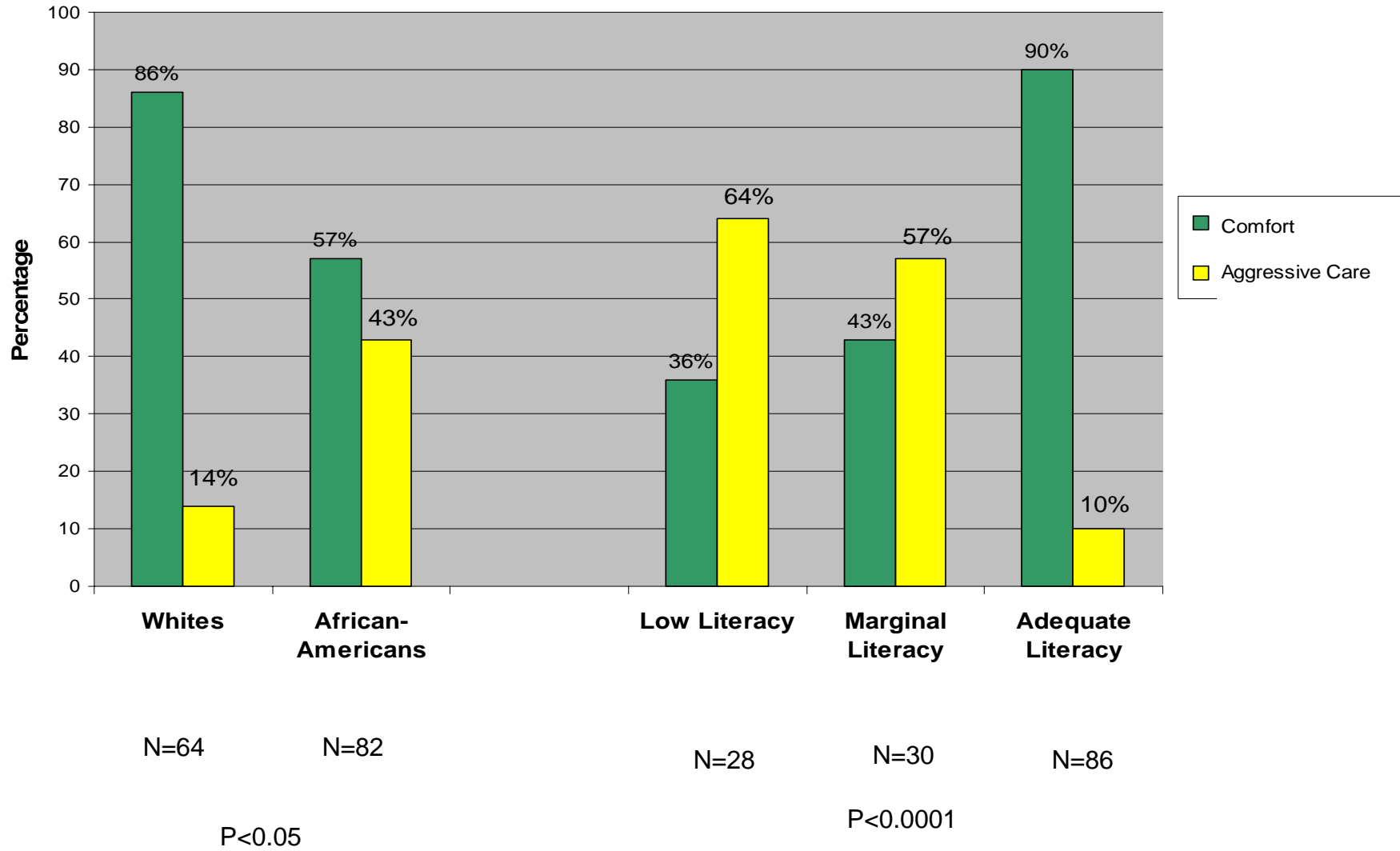
# Outcomes

- Primary outcome measures
  - Subject preferences after the verbal description
  - Change in preferences after the video
  
- Statistics
  - Adjusted logistic regression models
  - Health Literacy (Low, Marginal, Adequate)

# Results

Total number of subjects	146
Age, mean (SD)	57 (11)
Women, No. (%)	93 (64)
Race, No. (%)	
White	64 (44)
African-American	82 (56)
Education, No. (%)	
HS or less	82 (56)
College or beyond	64 (44)
REALM	
Low (0-45)	27 (19)
Marginal (46-60)	30 (21)
Adequate (>60)	87 (60)

### Preferences After Verbal Description by Race and Health Literacy

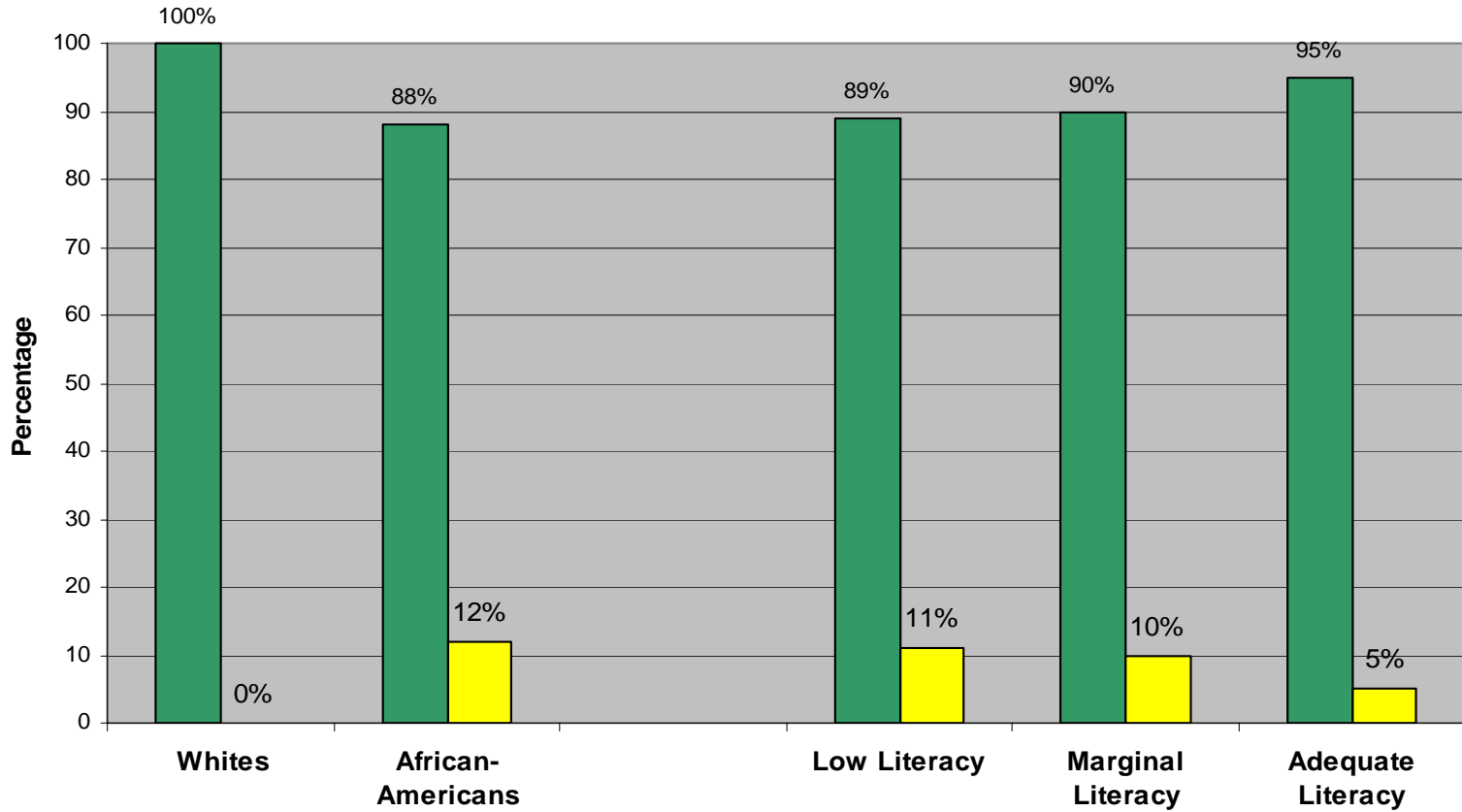


# Adjusted Odds Ratios

Race	Preferences for <b>AC</b>	Preferences for <b>AC</b>
	<i>Unadjusted</i>	<i>Adjusted</i>
African-American	<b>4.8</b> (2.1-10.9)	1.1 (0.3-3.2)
<b>Health Literacy</b>		
Low	<b>17.3</b> (6.0-49.9)	<b>7.1</b> (2.1-24.2)
Marginal	<b>11.3</b> (4.2-30.8)	<b>5.1</b> (1.6-16.3)

# Video

### Preferences After Video by Race and Health Literacy



Whites

African-Americans

Low Literacy

Marginal Literacy

Adequate Literacy

N=64

N=82

N=28

N=30

N=86

P<0.0001

P<0.0001

# Conclusions & Implications

- Large shift of preferences to comfort care after the video implies:
  - Communication barriers
  - Intervention to surmount
  - Focus on patient education models

# Strengths & Limitations

- Generalizability

Southern African-Americans? Latinos? Asians?

- Stability of preferences

- Isolate the effect of video

# The VIDEO study

- **V**ideo
- **I**mages of
- **D**ementia for
- **E**thical
- **O**utcomes

- Michael Paasche-Orlow, MD, MPH
- Muriel Gillick, MD
- Fran Cook, DSc
- Shimon Shaykevich, MSc
- Elmer Abbo, MD, JD
- Lisa Lehmann, MD, PhD

➤ THANK YOU!

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