Trust, Communication, and Shared Decision Making among Racial/Ethnic Minority Cancer Patients

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Disclosures

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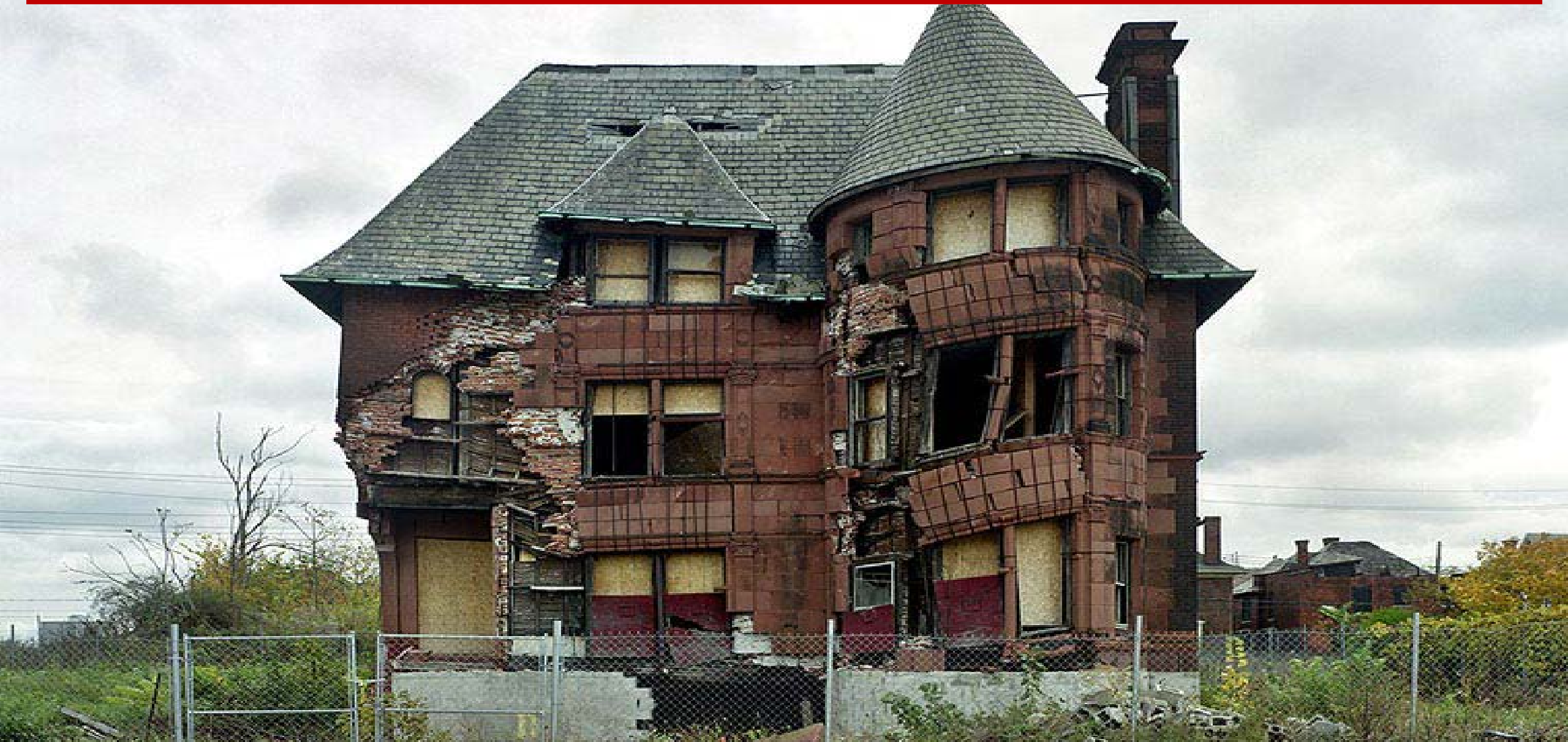
Race and SES influences on health



Objectives

- Review the relationship between patient race and quality of cancer care
- Describe the roles of trust and communication in decision making for cancer care
- Discuss the quality of decision making for cancer care among racial/ethnic minority patients
- Identify priorities for research and practice going forward

Race and cancer care
Evidence of an outcomes problem

Tumor type	5-year survival rate		Absolute difference
	Black	White	
Pancreas	4.6%	4.7%	0.1%
Liver	6.5%	9.1%	2.6%
Lung	12.2%	15.2%	3%
Esophagus	10.5%	16.8%	6.3%
Colorectal	55.5%	65.6%	10.1%
Breast	76.6%	89.8%	13.2%
Bladder	64.8%	83.2%	18.4%
Head & Neck	40.5%	62.1%	21.6%
Uterine	61.8%	86.4%	24.6%

Morris, Rhoads, Stain, Birkmeyer, JACS 2010

Linking process to outcomes
Stage II-III rectal cancer (SEER-Medicare) – B v. W

- Adjuvant chemotx → 5y OS benefit 17%, DFS benefit 25%

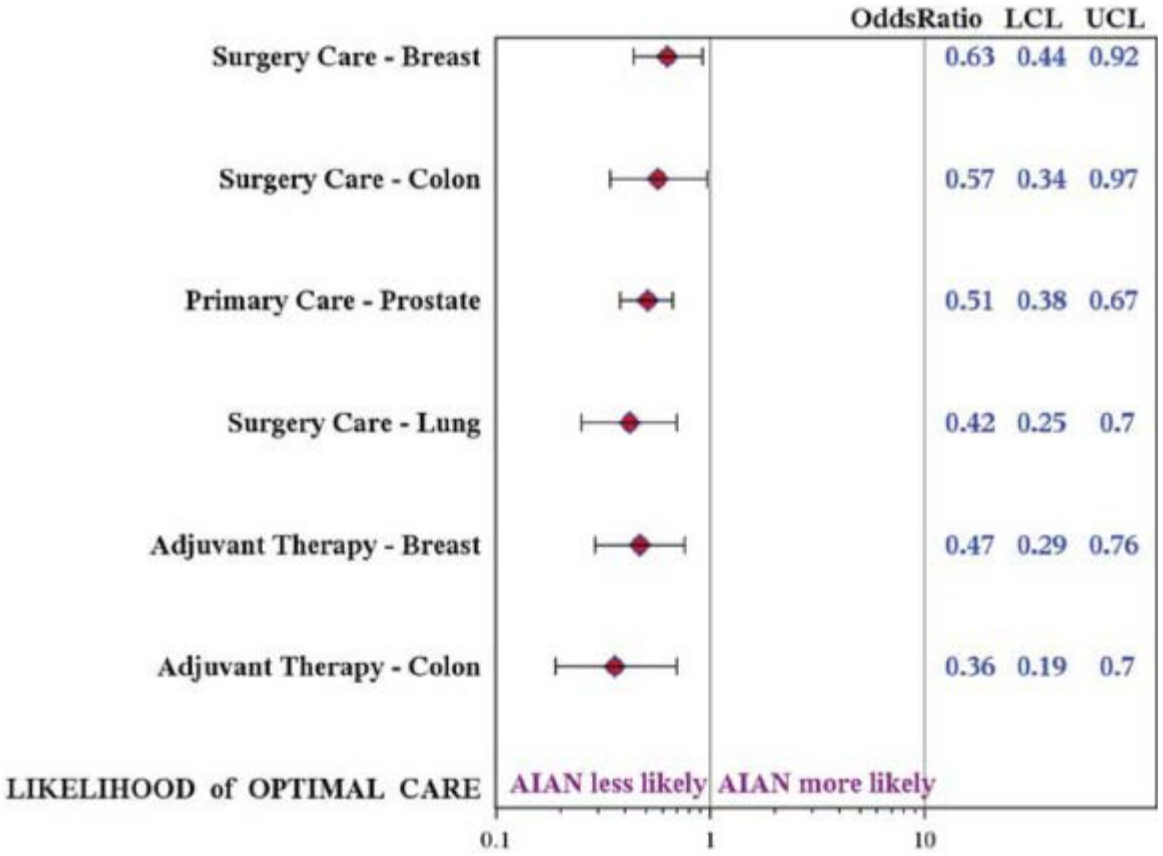
Petersen et al, Cochrane Database of Syst Rev 2012

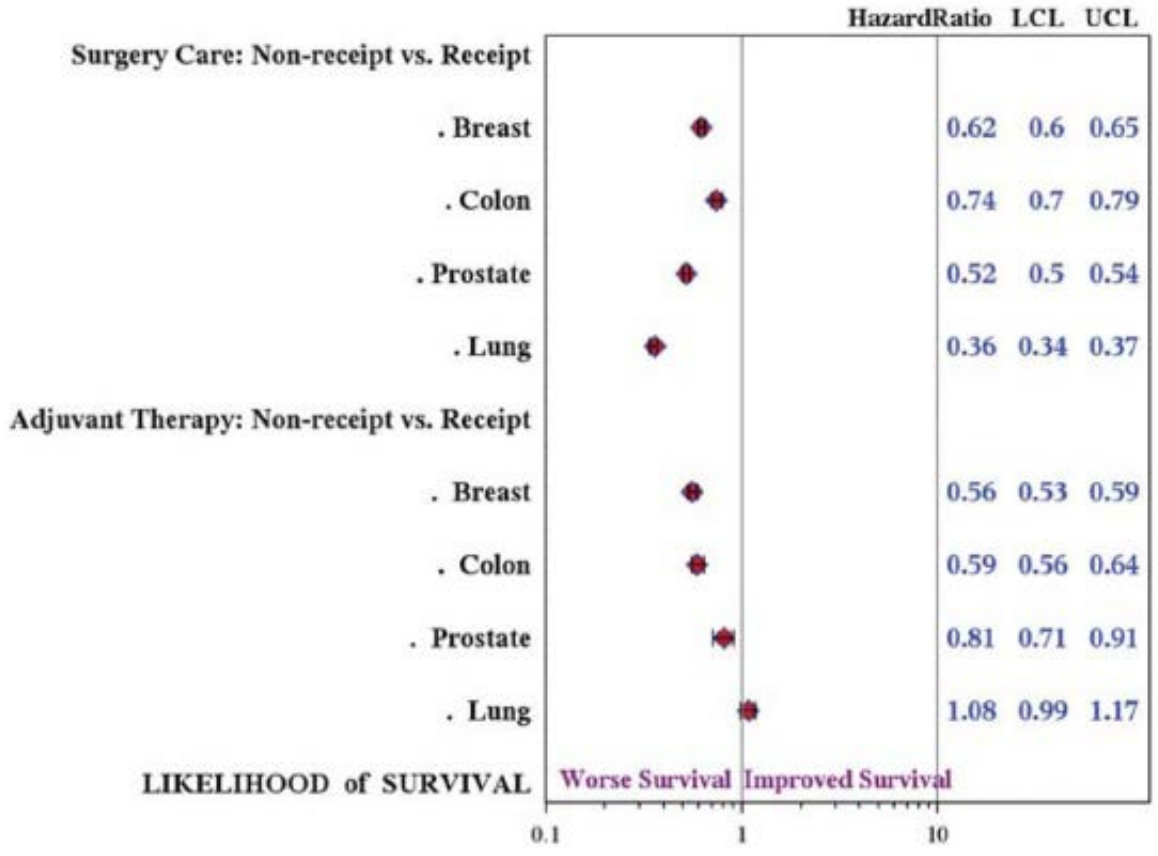
- 1992-03 SEER data, Rectal cancer resection
- 18% B:W 5y OS difference – primarily mediated by income / comorbidity
- 20% B:W disparity in use of any adjuvant therapy
- 33% B:W disparity in use of chemotx

Morris, Wei, Birkmeyer, Birkmeyer, JACS 2006

Linking process to outcomes

Breast, lung, prostate, CR cancers – AI/AN v. W

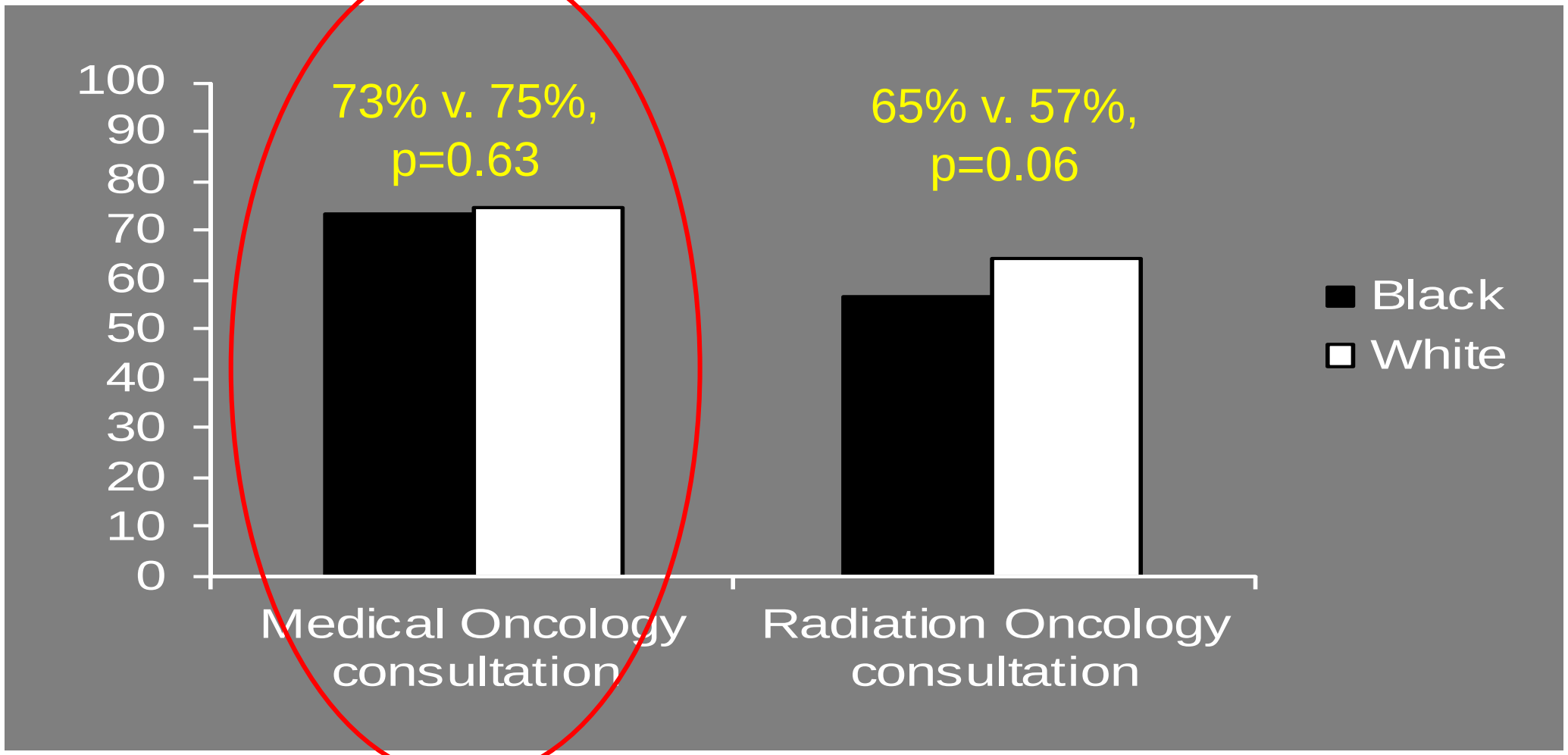




Javid, et al, Cancer 2014

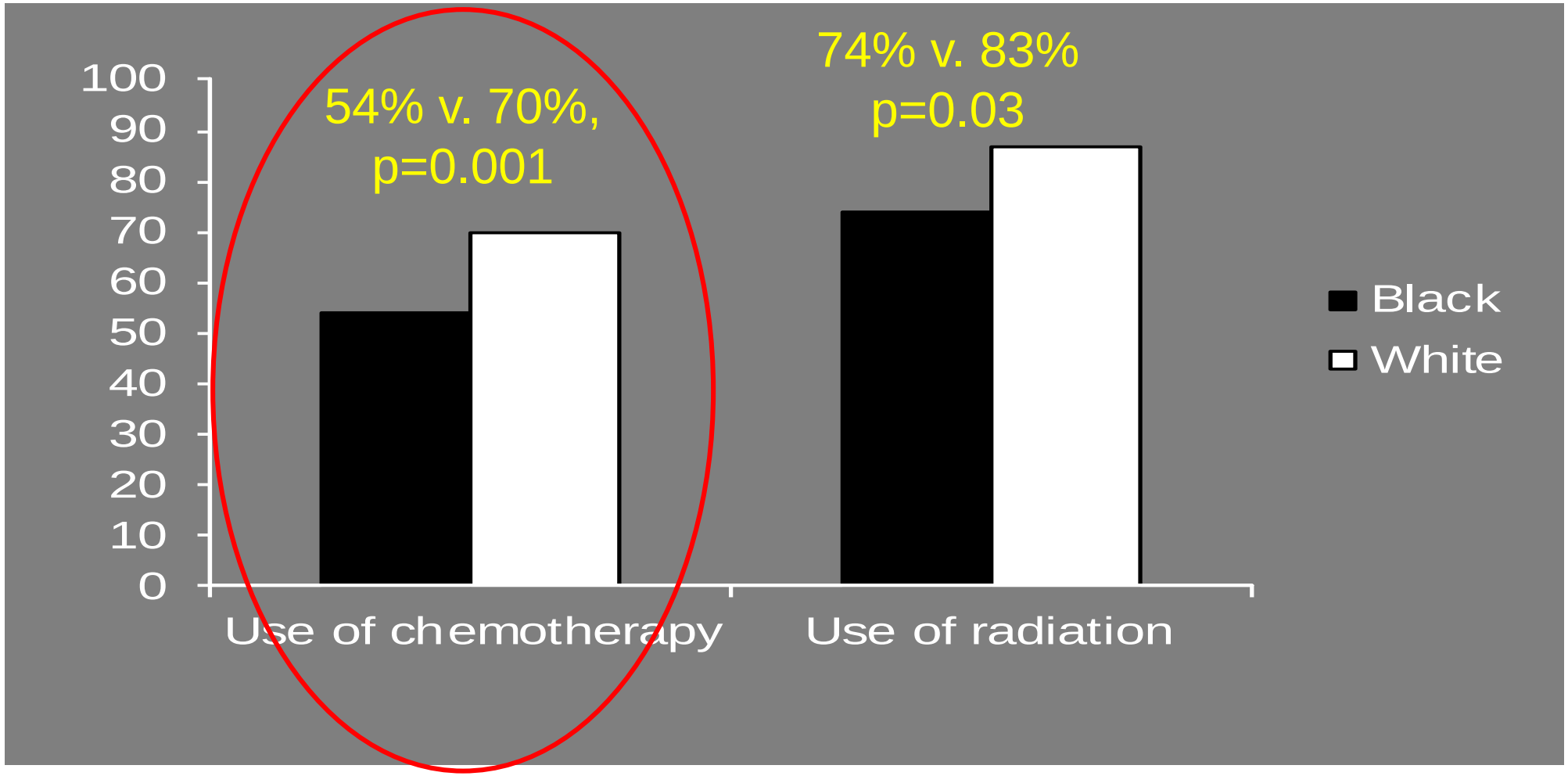
Why are black and AI/AN patients with identical healthcare coverage so much less likely than whites to receive guideline concordant cancer care?

Pt race and oncologist consultation after surgery



Morris et al, JNCI 2008

Pt race and receipt of adjuvant tx *after* consultation



Morris et al, JNCI 2008

Trying to explain omission of chemotx for black pts

- Unadjusted RR = .76 (0.62, 0.91)
- SEER-Medicare linked to Census, AHA, AMA
  - Age + gender + marital status + median income
  - Comorbidity + cancer stage + length of stay
  - Oncologist volume + board certification + years in practice
- Adjusted RR = 0.83 (0.67, 0.98)

The limitations of quantitative data

Missing key details

"The poor are getting poorer, but with the rich getting richer it all averages out in the long run."


“Race and patient perspectives on use of chemotherapy”

An adapted model of equity in utilization of care

Patient needs care

Patient wants care

Patient gets care

Andersen and Aday, Health Serv Res, 1974

Methods
Iterative sex/race concordant focus groups (n=6/49)

- Queried subjects wrt
  - Predisposing/enabling factors
  - Pt-MD relationship
  - Satisfaction and regrets
- Analysis
  - Audiotaped and transcribed interviews
  - Developed and tested a coding dictionary
  - 3 independent coders, constant comparative analysis
  - Discussed to consensus, adjudicated by PI
  - Incorporated emergent themes into prompts for subsequent groups

Results
Mapping themes

Patient needs care

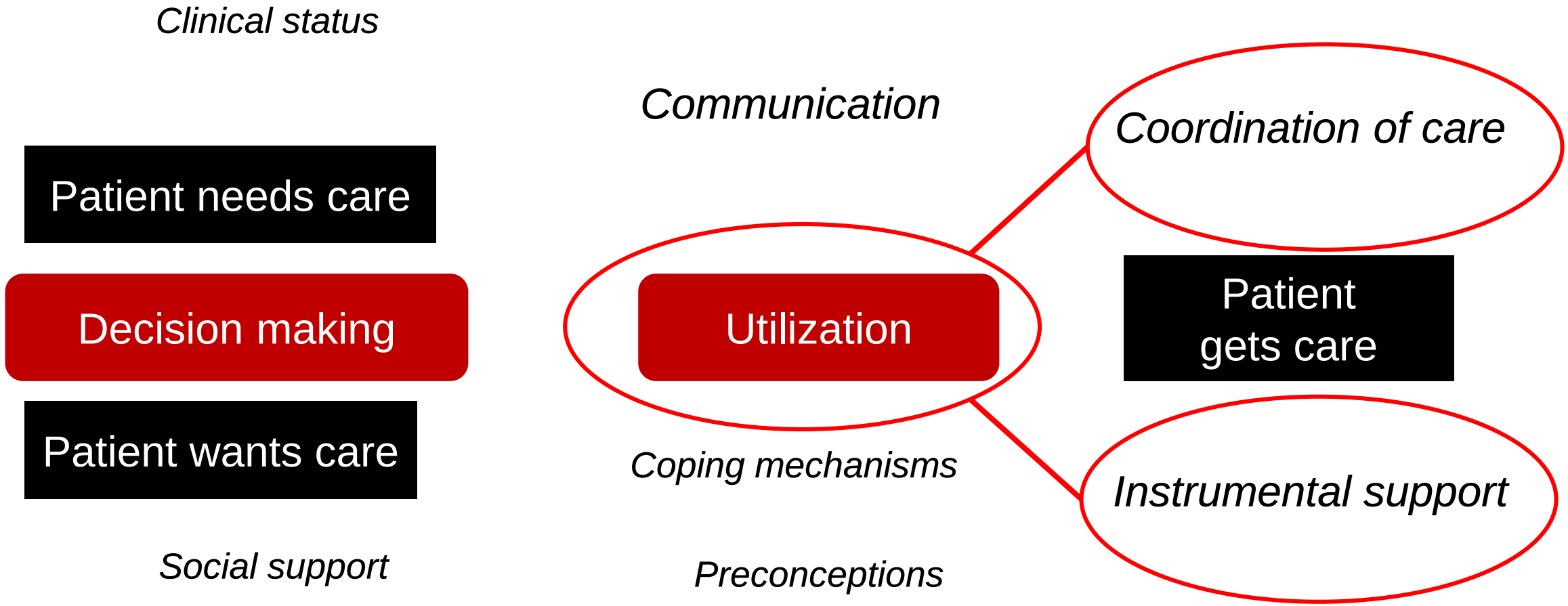
Decision making

Patient wants care

Utilization

Patient gets care

Mapping themes



Coordination of care

≥ 2 providers communicating about 1 pt

- Crossed ethnic lines
- SES-related self-efficacy

- WF (affluent): *"…when I pressed her [the family doctor], she gave me the name of the top-top colon cancer guy … I didn't want to wait till after the Holidays, and we were accommodated beautifully..."*

- WF (poor): *"I was in the emergency room probably 8-10 times with it in four months because I was in so much pain and I'm like, "You've got to figure out what's wrong with me. I can't—" I couldn't stand up, you know, I—I work in fast food. You're—you stand up all day (laughs)."*

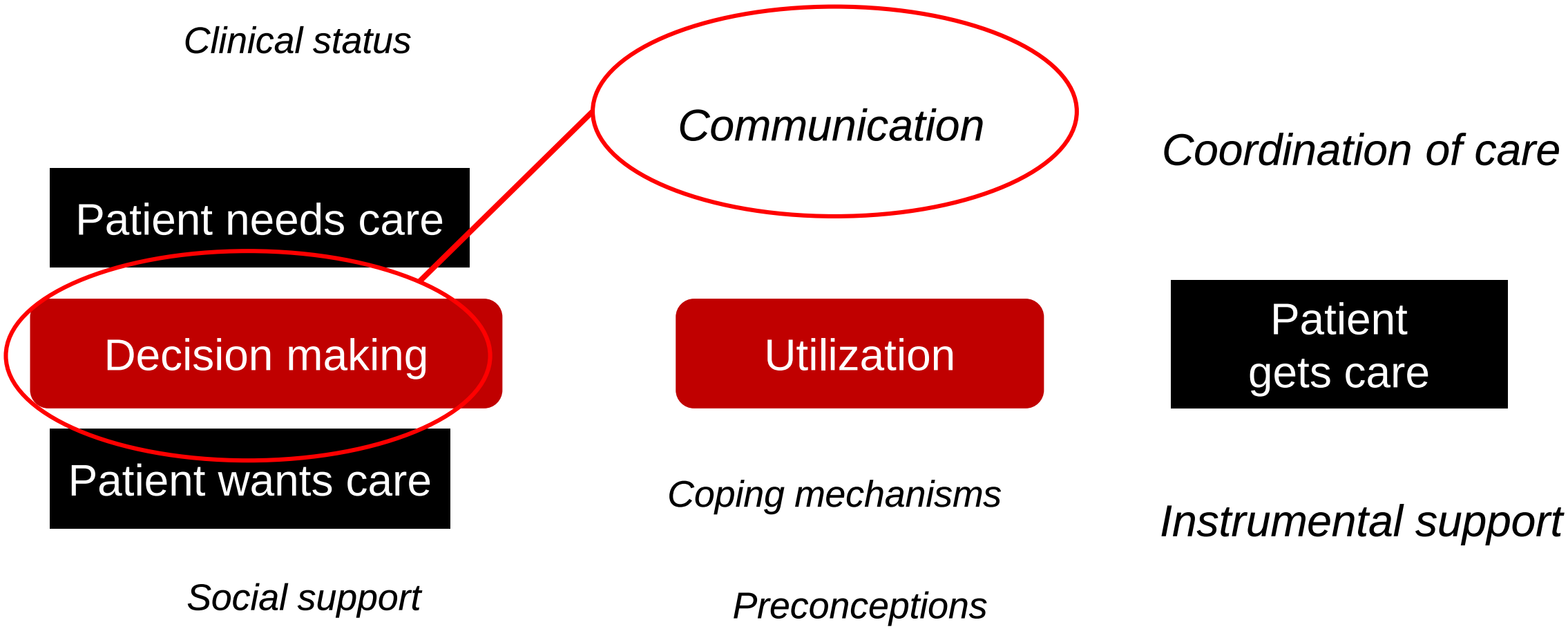
Instrumental factors
Anything with a $ value

- Crossed ethnic lines
- SES-related hierarchy of needs

- AAM: *"I—it's hard to find a job right now to get health insurance…And I've had thoughts of, you know, "It would be easier if the cancer came back and was to just, you know, succumb my life."*

- WF: *"… we only get 12 weeks, um, short-term sick leave—medical leave and so I had spent half of the six months fighting to keep my job and I'd—I'd go into debt. Seriously into debt because I—I support myself. I don't have a husband or a roommate to help me pay everything."*

Mapping themes



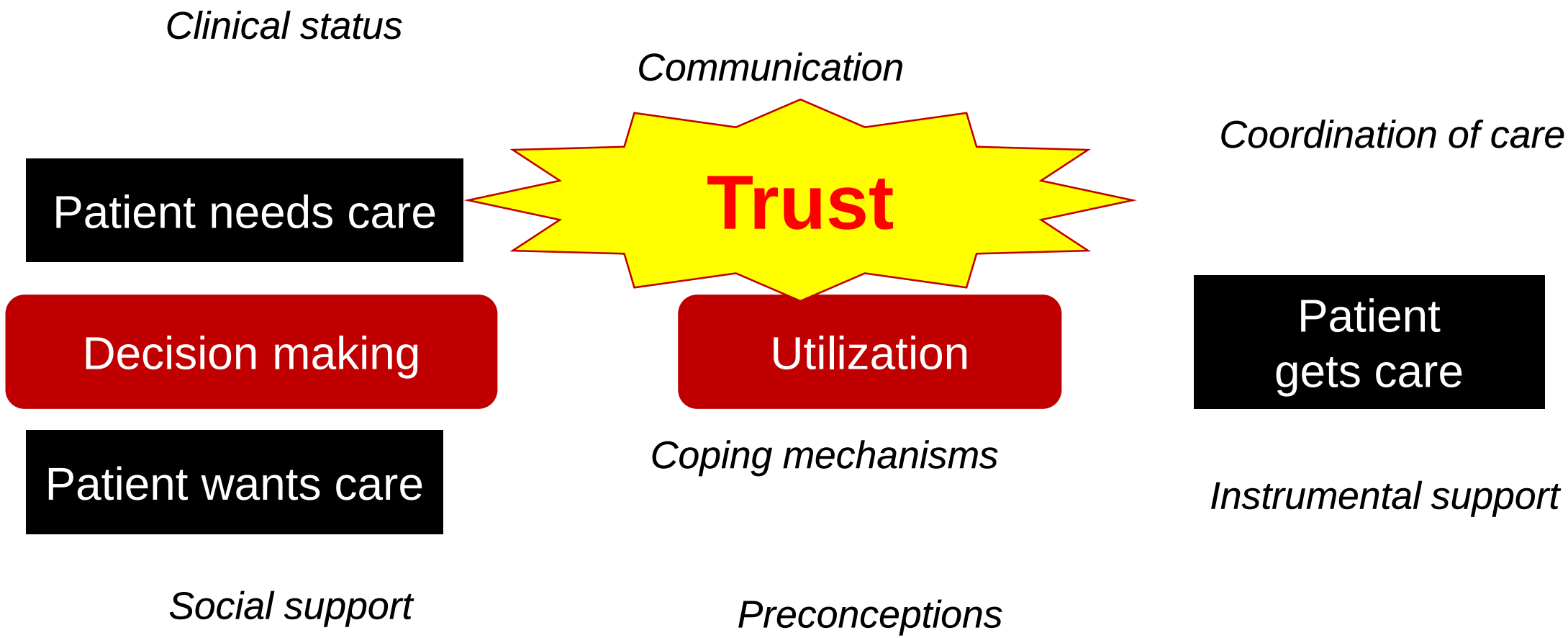
Patient-centered communication
Informative, supportive, relationship building

- Supportive vs. informative
- Uni-directional based on major literacy & numeracy issues

- WF: *"And he came in and he said, "You are a very sick little girl but we're going to take care of this…Keep your chin up" …he is the most wonderful, compassionate, sweetest man, you know."*

- AAM: *"he gave me this baggie and …Um, 65% of it would never come back and, uh, this and that, and this and that. And then, um, the chemo would just give me another 10%...But I looked at it like …I could get hit by a bus walking out here to go to my car. And there goes that 10% I spent on——the therapy."*

Mapping themes



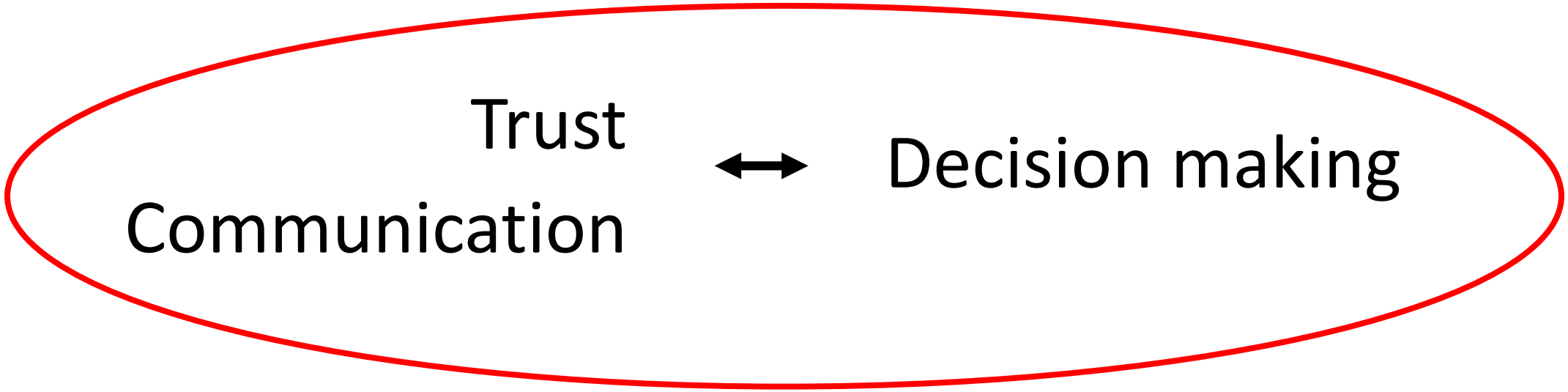
Trust
The optimistic acceptance of vulnerability

- White: unshakable trust in MD as reason for use
- Black: lower trust in MDs and health system, expressed differently by Rs of different SES

- WF: *"Well, he said, "You'd be treated by chemotherapy" and I just left it up to him …I just believe in him and God and, uh, went on through with it."*

- AAM: *"because of …an attitude among African Americans about the medical field. I don't think there is a comfort level with the medical field…African Americans don't feel comfortable with being, you know, associated with, uh, the medical field I guess. … you know, going to see a doctor and—and getting things taken care of."*

Summarizing the qualitative data

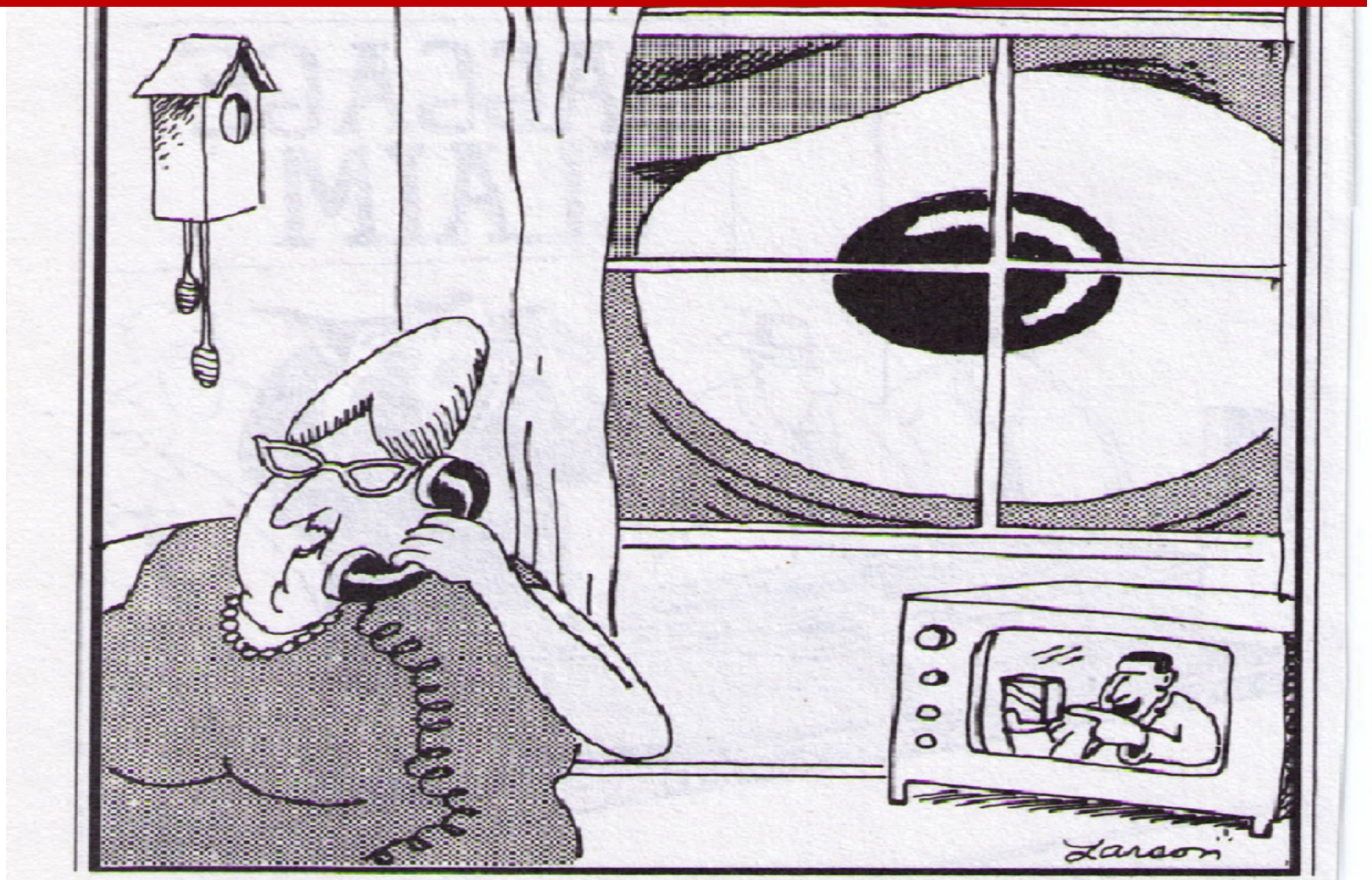


Coordination of care
Instrumental support
Utilization of chemotx

The limitations of qualitative data

Missing the big picture

- Validation?
- Generalizability?
- Implications?

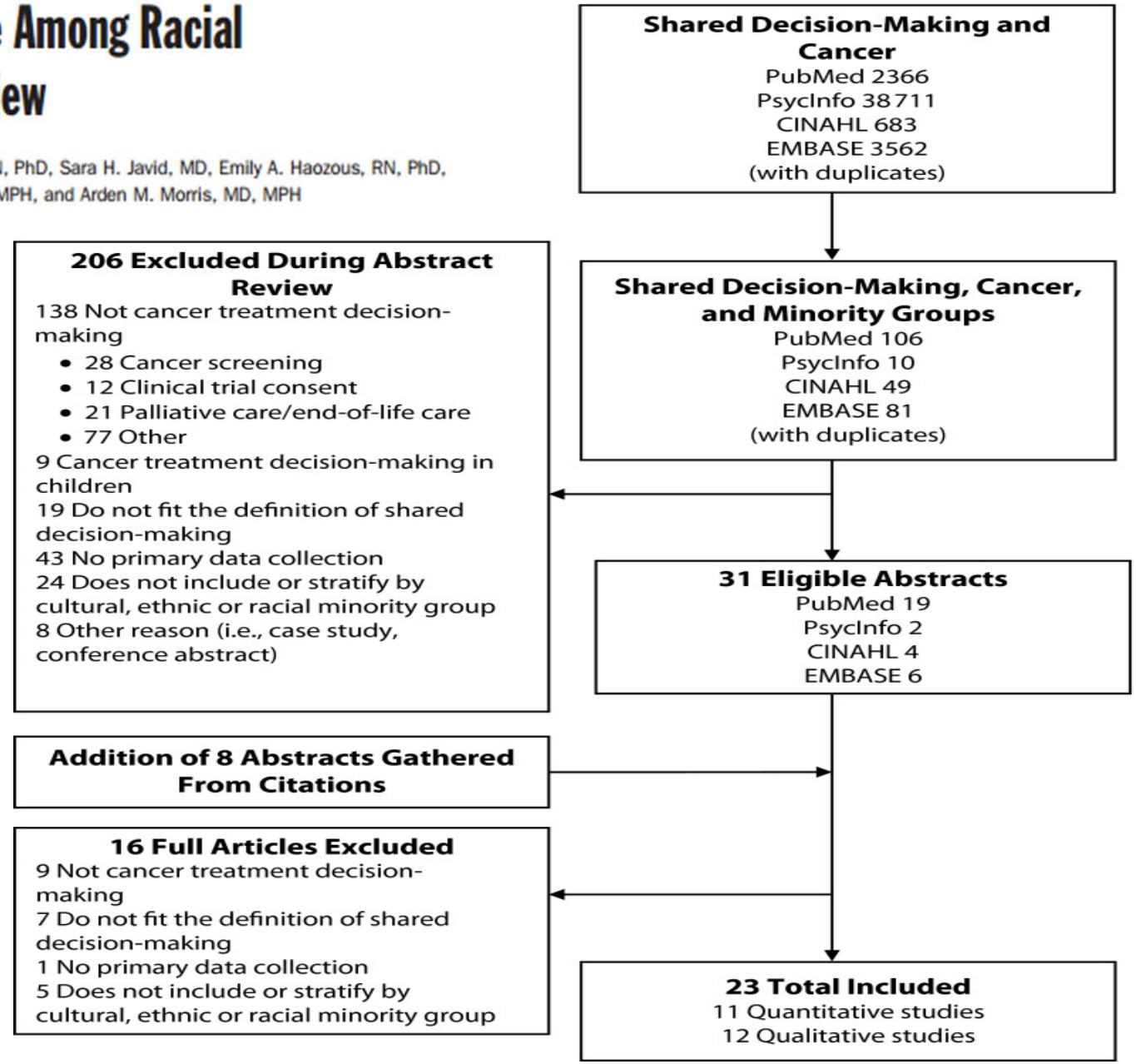


"Hello, Emily. This is Gladys Murphy up the street. Fine, thanks . . . Say, could you go to your window and describe what's in my front yard?"

Shared Decision-Making for Cancer Care Among Racial and Ethnic Minorities: A Systematic Review

To assess decision-making for cancer treatment among racial/ethnic minor-

Erin L. Mead, MHS, Ardith Z. Doorenbos, RN, PhD, Sara H. Javid, MD, Emily A. Haozous, RN, PhD, Lori Arviso Alvord, MD, David R. Flum, MD, MPH, and Arden M. Morris, MD, MPH



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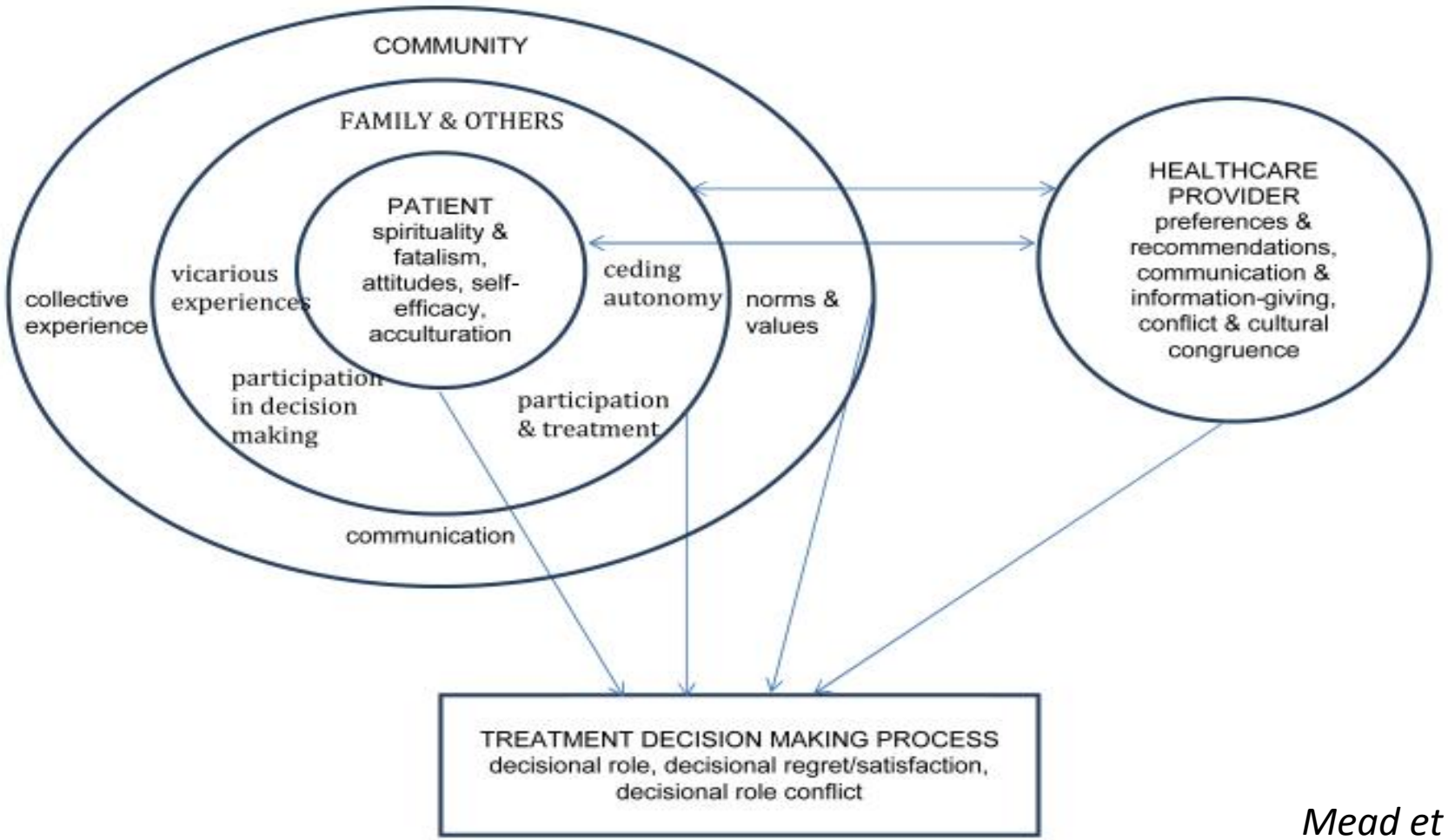
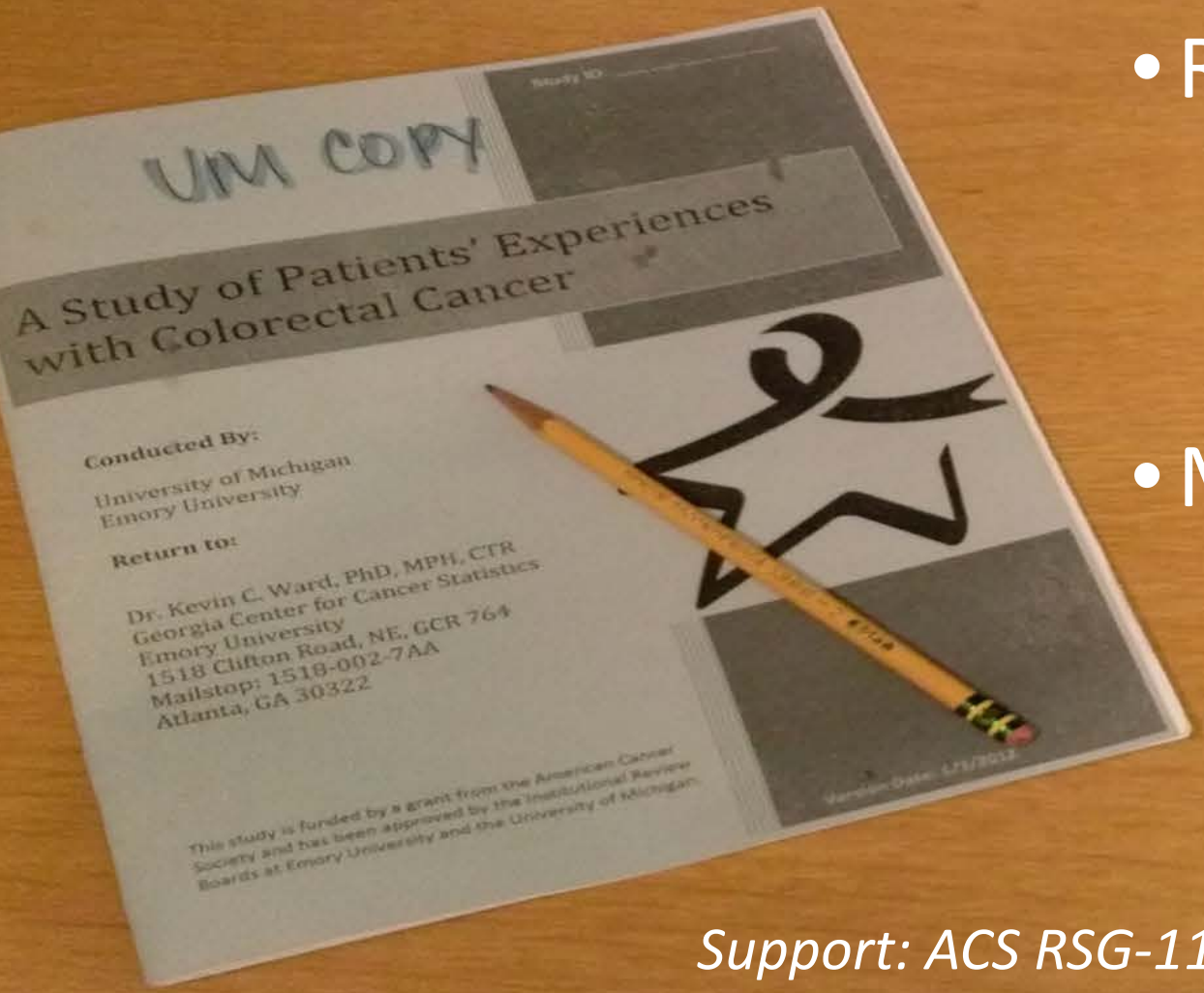


Mead et al, AJPH 2013

Theme	Examples from research
Decision making for treatment	Understanding risk/benefit information Priorities in DM Actual and preferred decision role Decision outcomes
Patient factors	Personal beliefs Spirituality Trust in providers Perceived discrimination
Provider factors	Knowledge, Attitudes, Beliefs Communication style Cultural competence
Family and important others	Role of others in DM, Social support, Vicarious experience
Community factors	Networks, social support, social norms

Population based surveys: Detroit, Atlanta/GA, L.A.

Stage III CRC, n=1425, 68% response rate

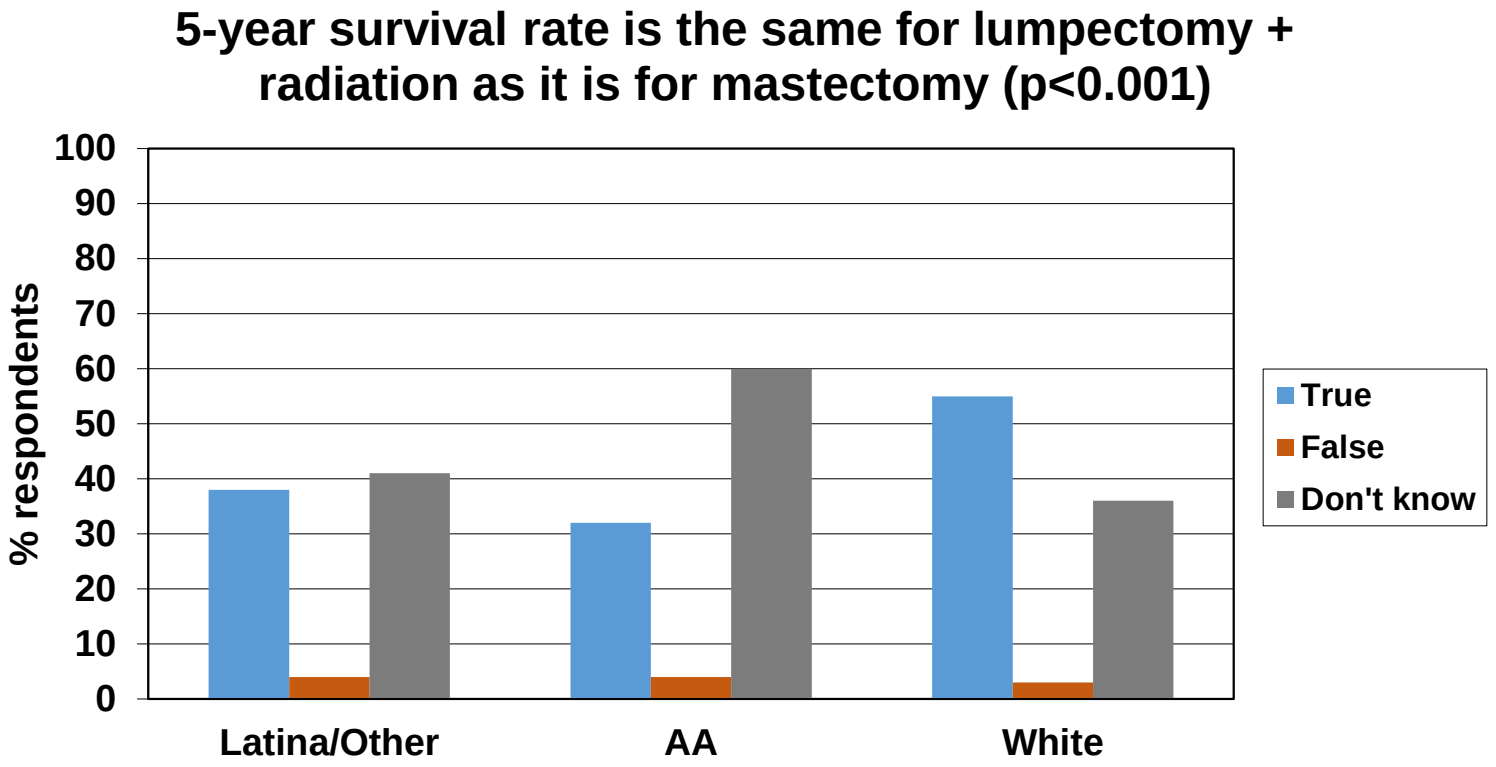


- Recruitment
  - Rapid Case Ascertainment
  - Population based
  - Mixed mode
- Measurement
  - Validated instruments
  - Cognitive interviews
  - Redundancy: Qs and data entry

Support: ACS RSG-11-097-01-CPHPS, R01-CA109696, R01-CA088370

Characteristics	Black, N=335 (%)	White, N=917 (%)	p-value
Age - Mean(sd)	64.8 (13.3)	61.1 (12.6)	0.1164
Sex - male	54.5	50.3	<.0001
Education			<.0001
< High School	13.3	24.9	
High School	24.7	26.8	
Some College or more	33.0	32.3	
College Grad +	29.0	16.0	
Income			<.0001
<$20,000	16.9	38.6	
$20,000-$49,000	32.1	34.7	
$50,000 - $89,000	28.0	21.3	
$90,000+	23.0	5.5	

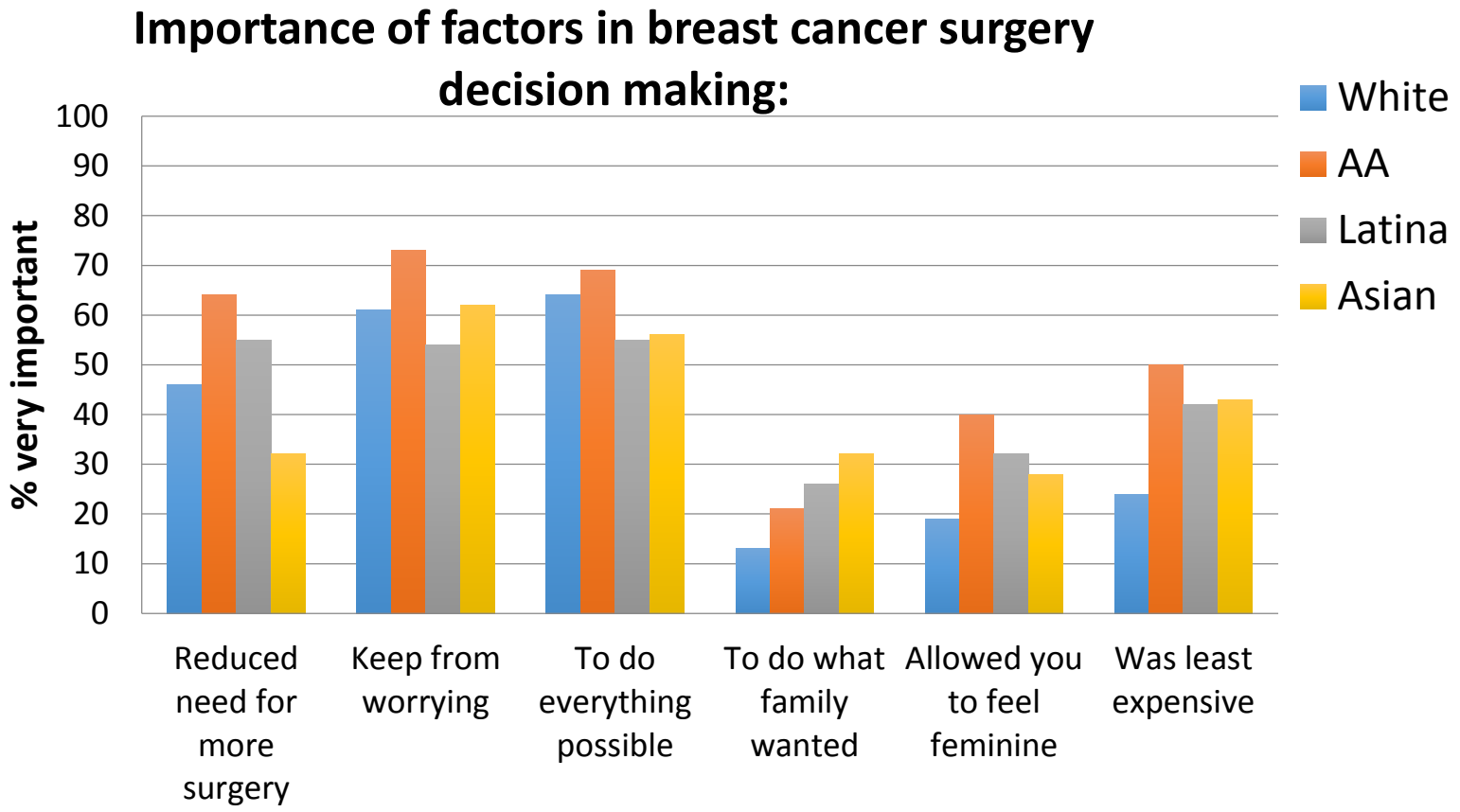
Decision making for treatment
Understanding risk/benefit information



Hawley et al., HSR 2008

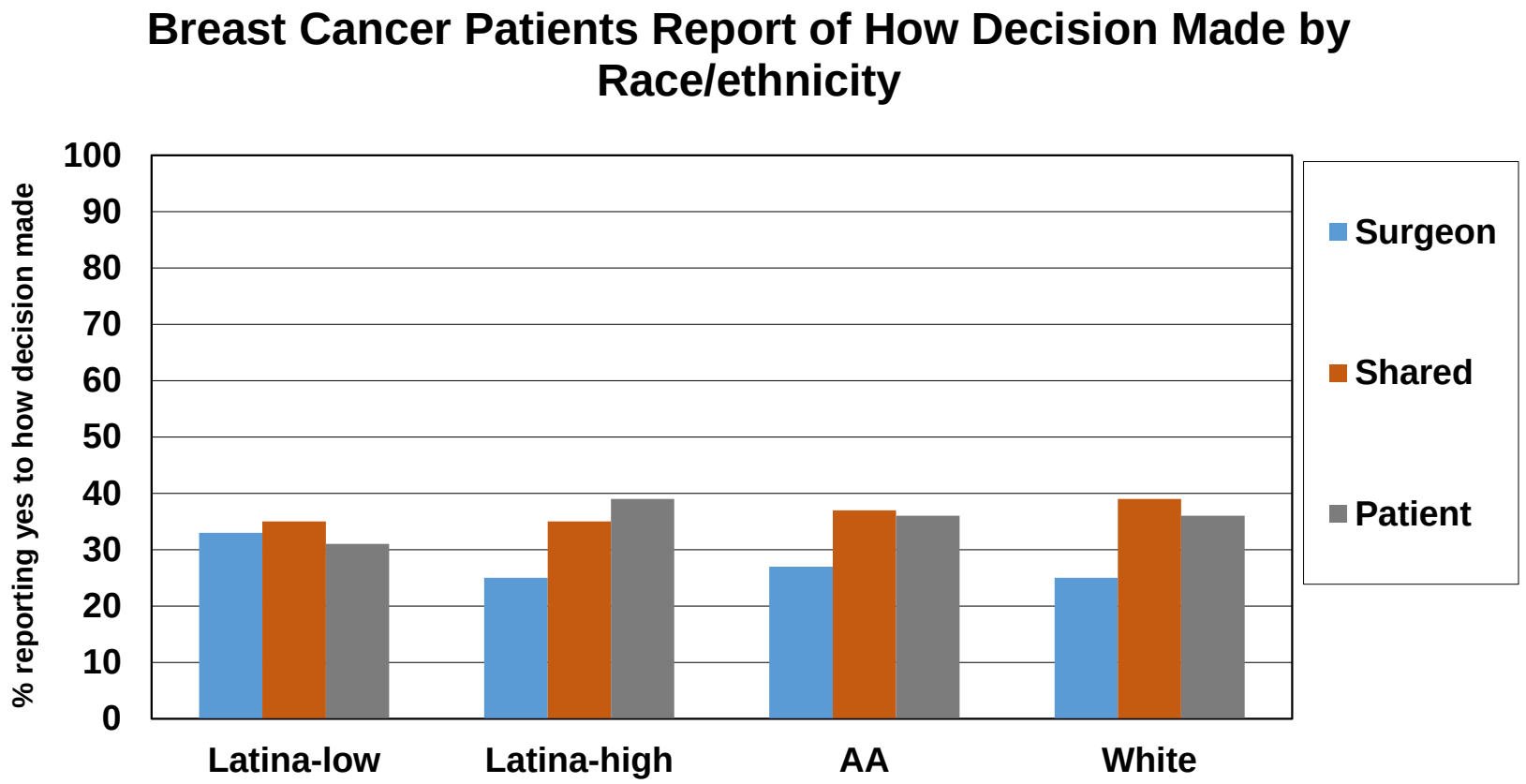
Decision making for treatment

Patient priorities in treatment selection



-Hawley et al. PEC 2008

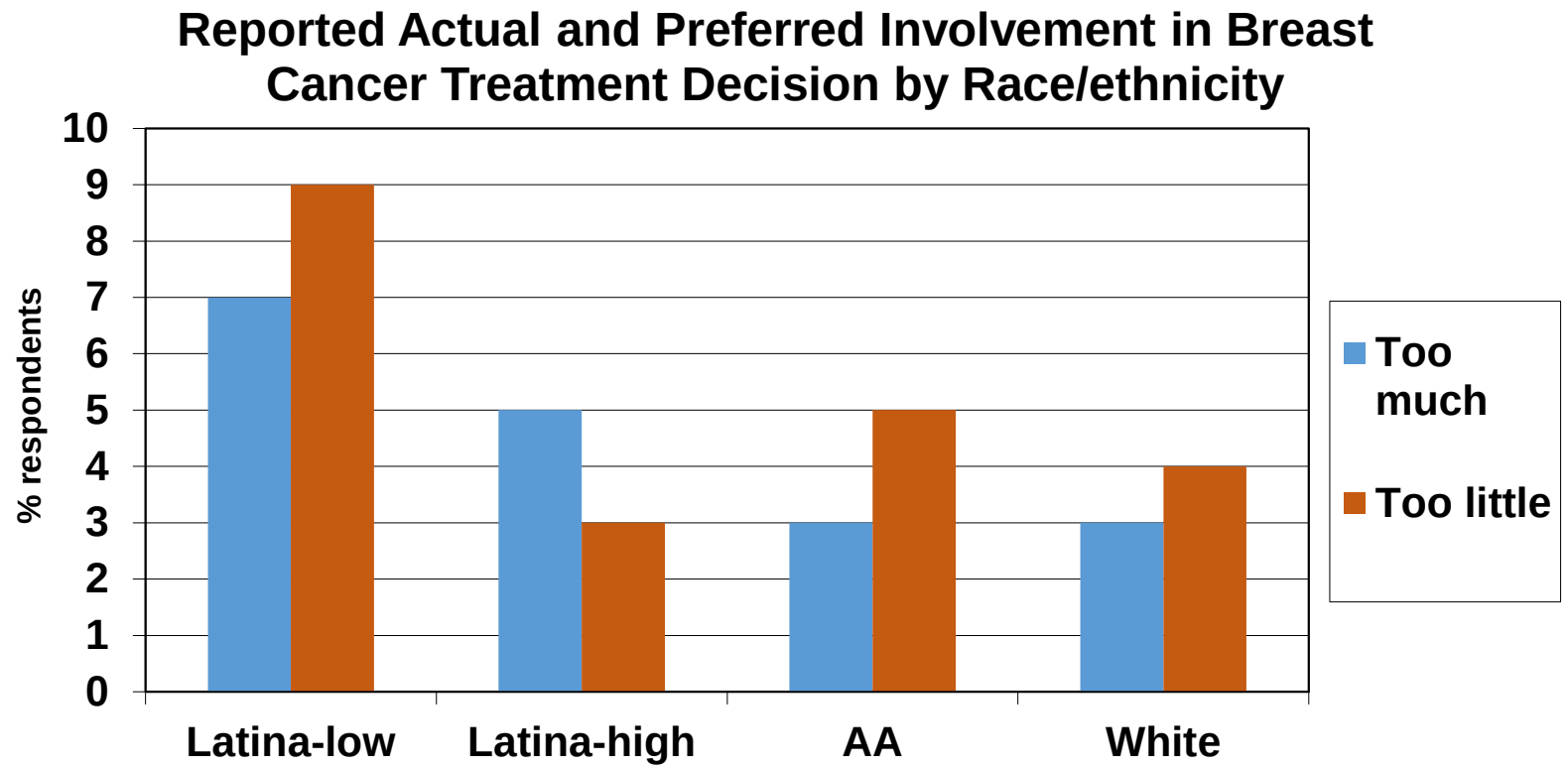
Decision making for treatment
Actual decision role by race/ethnicity



Stage 0-II and no clinical contraindications to BCS; adjusted for demographic and clinical factors and sampling weights applied.

-Hawley et al. JNCI 2009

Decision making for treatment
Match btw actual-preferred DM role by race/ethnicity

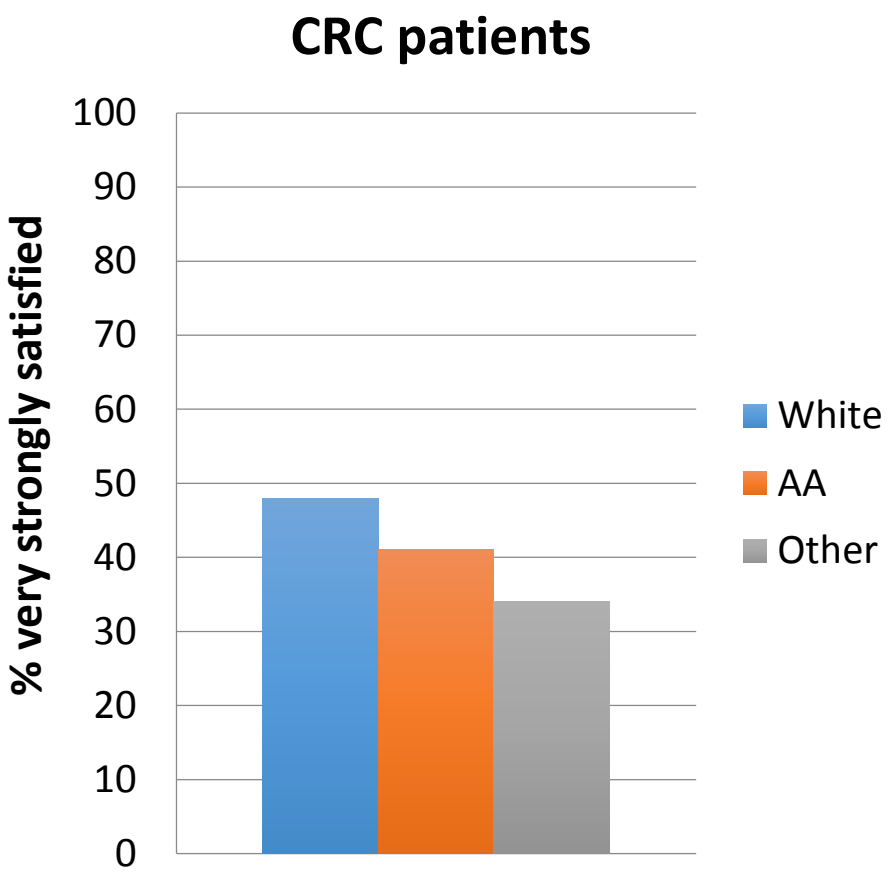


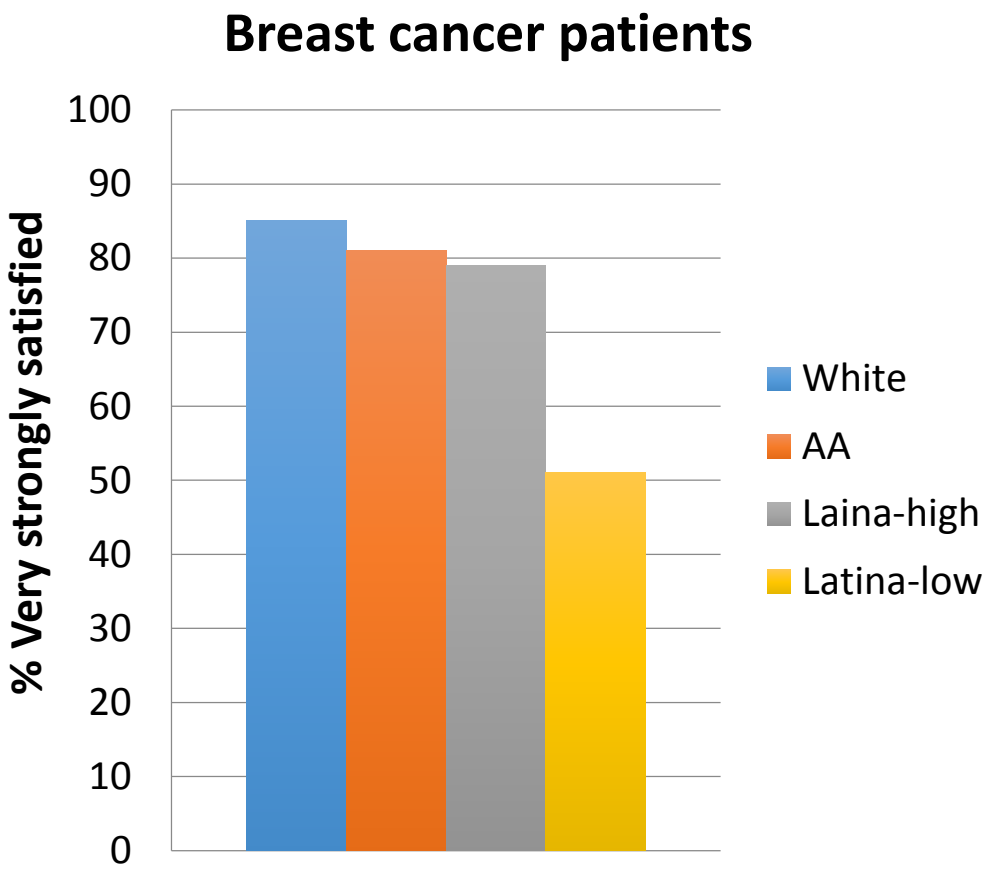
Adjusted for demographic and clinical factors and sampling weights applied.

-Hawley et al. PEC 2008

Decision making for treatment

Decision satisfaction by race/ethnicity

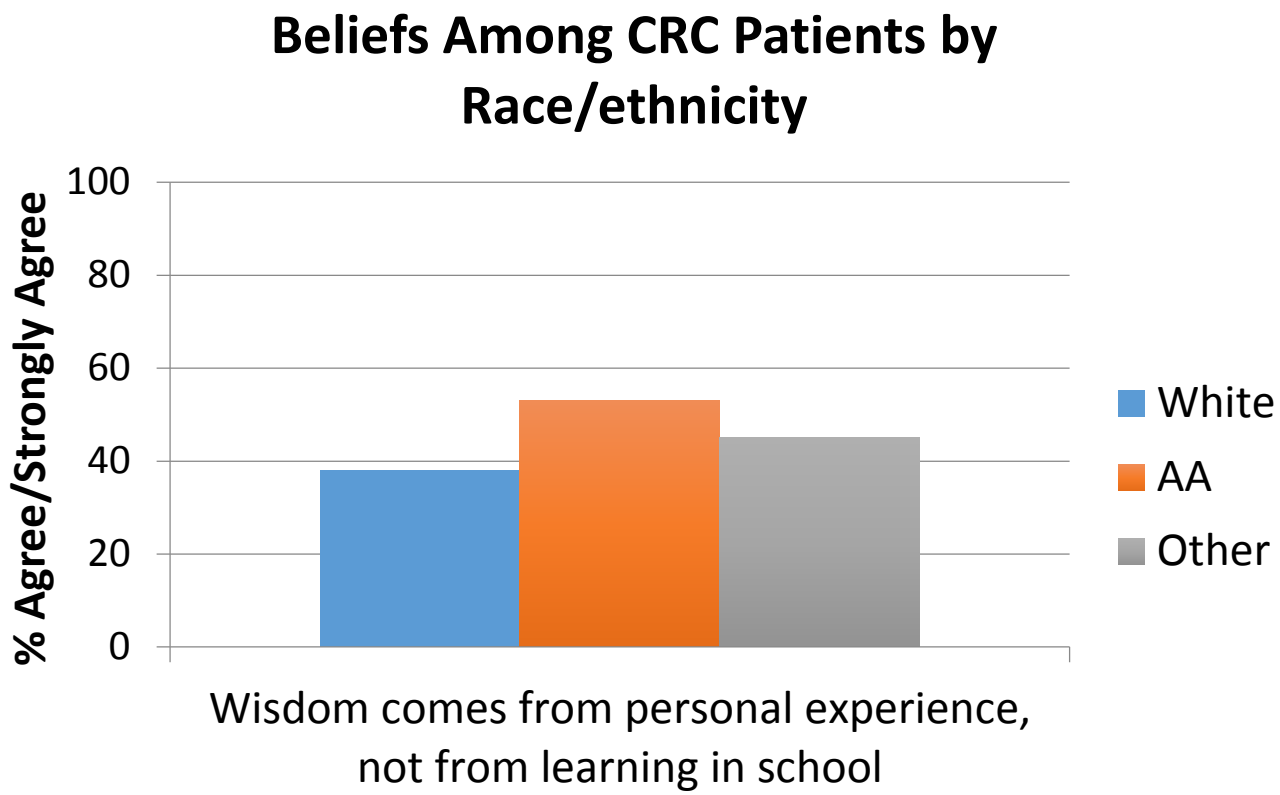




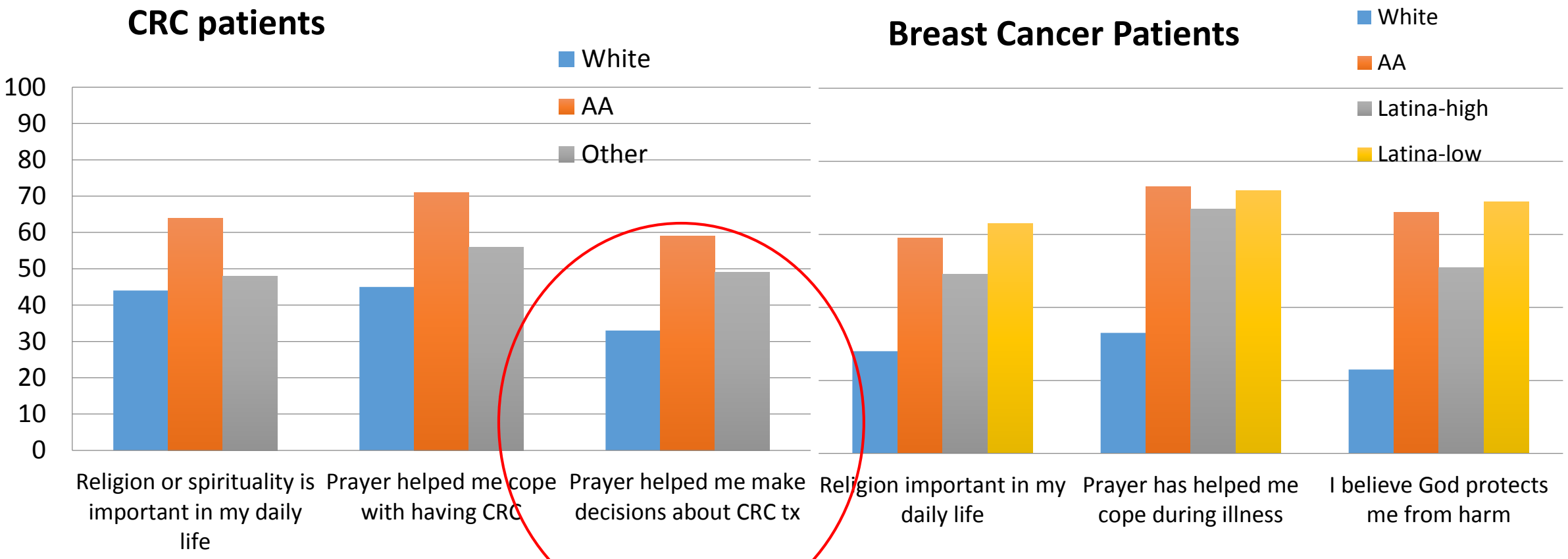
-Hawley and Morris. PEC, In Press

-Hawley et al. PEC 2008

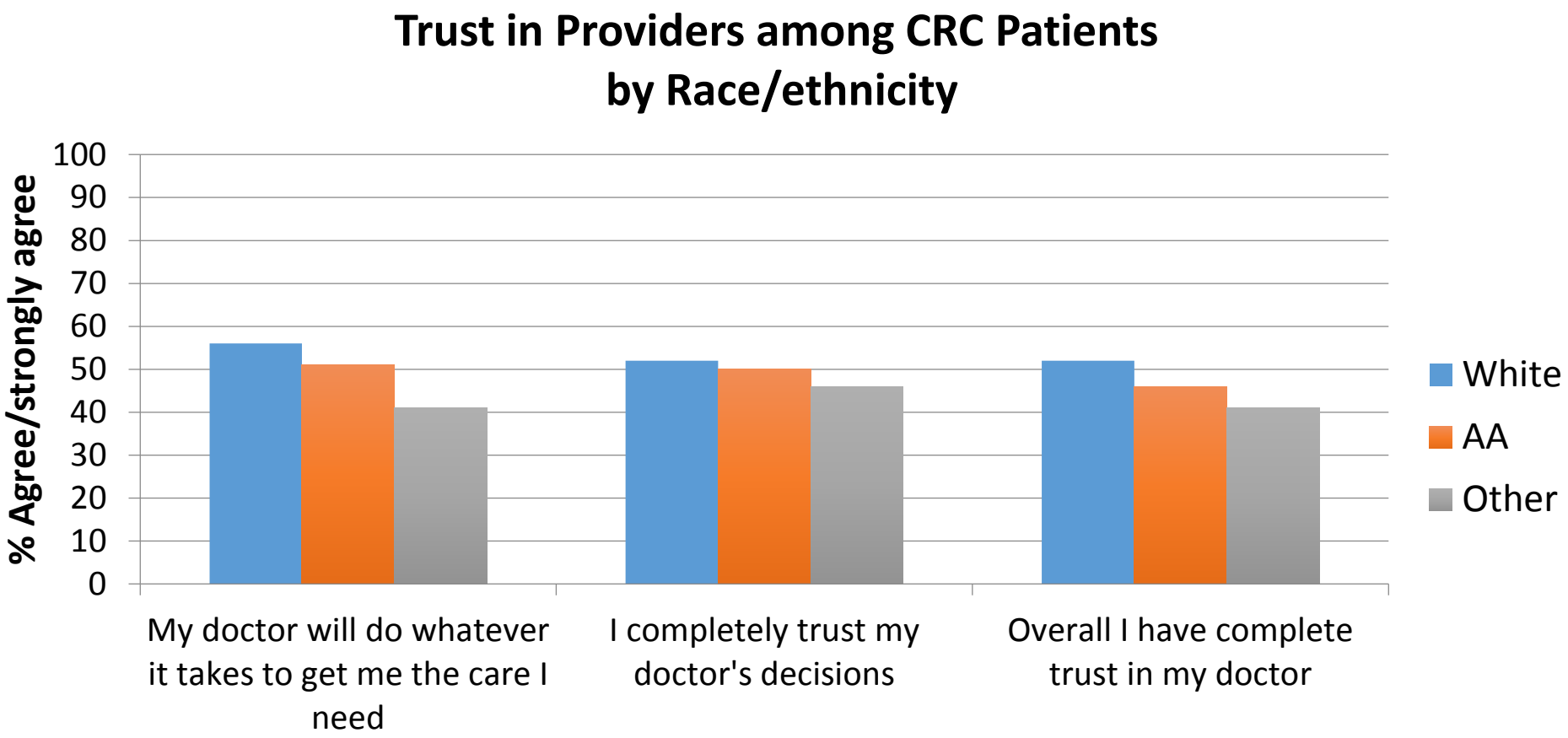
Patient factors
Personal beliefs, e.g. ways of knowing



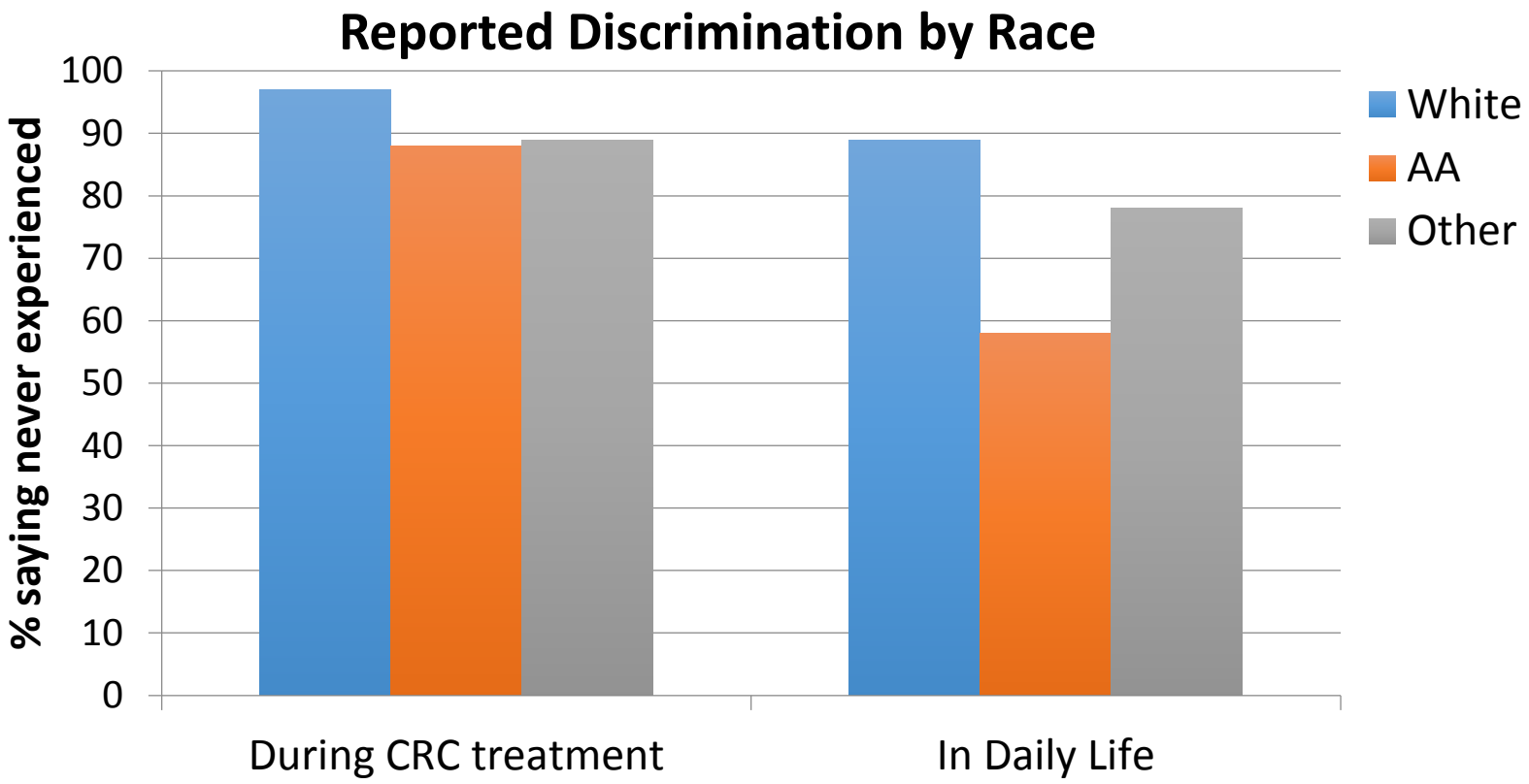
Patient factors (CRC)
Spirituality



Patient factors
Trust in providers



Patient factors
Perceived discrimination

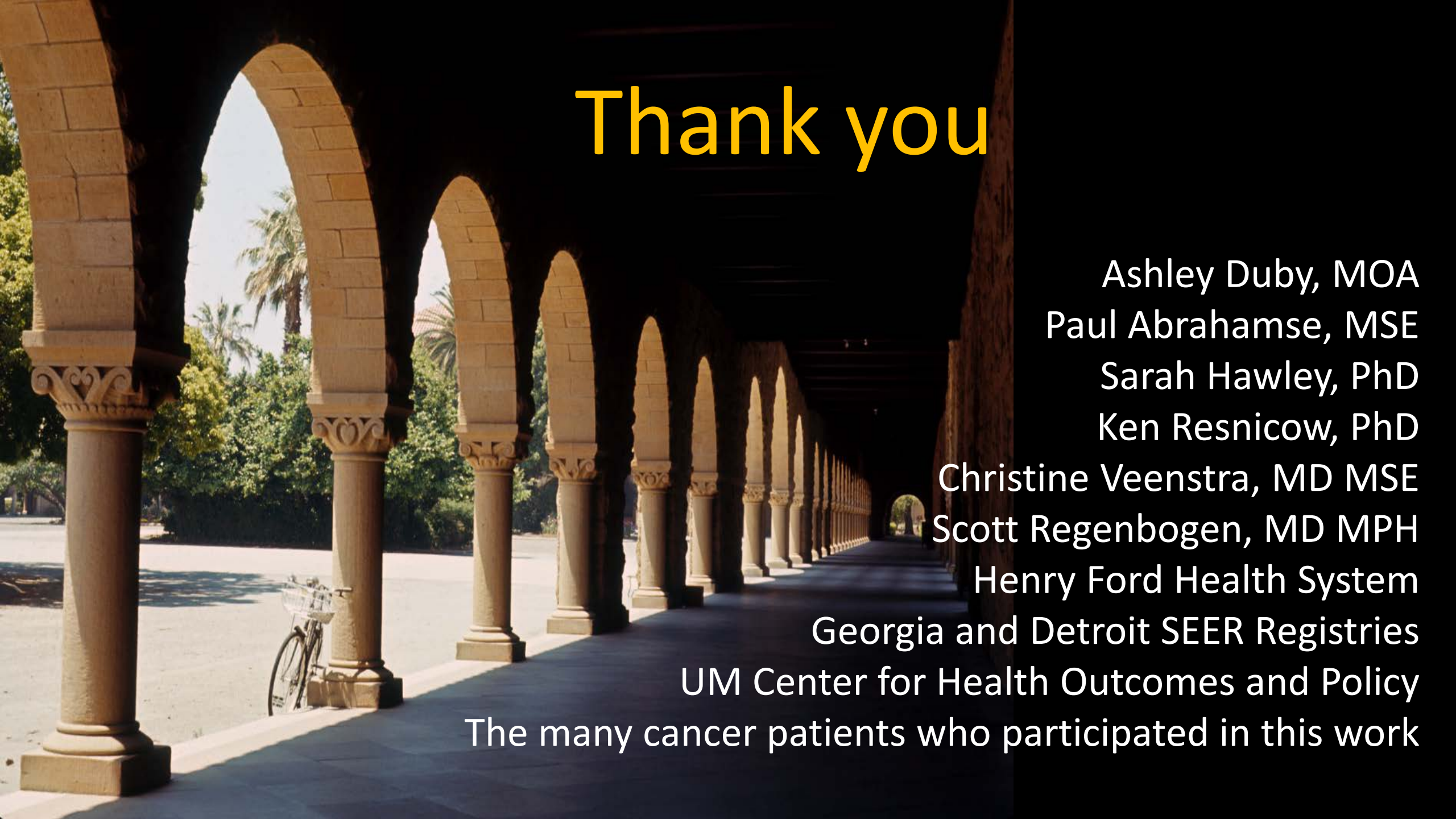


In summary

- Disparate adherence to standards of cancer care → disparate outcomes
- Non-adherence is more than just an access problem
- Little to no evidence of explicit discrimination in the pt-provider interaction
- Racial/ethnic Δ in trust, communication → Δ quality of DM for care

Recommendations going forward

- Novel metrics for “culture” beyond race/ethnicity; a robust model to understand how culture shapes preferences
- Innovative methods to convey risk/benefit information to patients from different cultural backgrounds (*eg* adapted rating/ranking)
- Tailored DM interventions that accommodate differences in belief systems, perceived discrimination, and lack of trust in health system (*eg* TIMCP)
- Appropriate inclusion of family & important others; expansion of SDM beyond the classic pt-MD dyad



Thank you

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