Self-Management?

Literacy---------->Outcome

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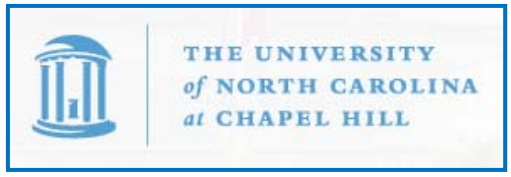


- NHLBI R01 HL081257 

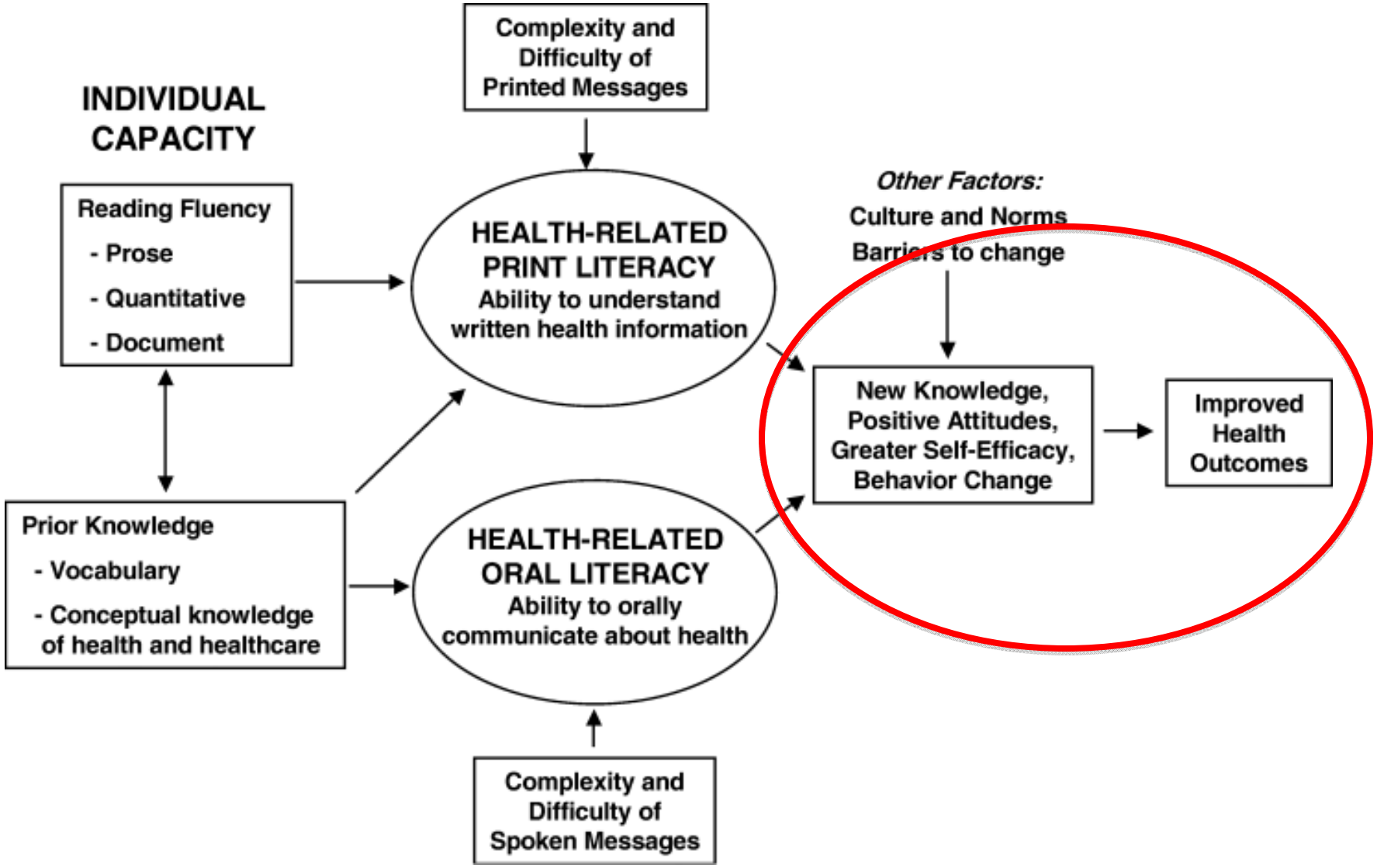
- NIDCR R01 DE018045 

“Every scientific field makes certain simplifying assumptions about the complex reality that it studies. Such assumptions are built into the intellectual paradigm that guides a scientific field.”

Everett Rogers. Diffusion of Innovations, 5th Ed. 2003.

Self-Management and Literacy

- Cross-sectional studies show literacy's relationship with knowledge and behaviors
- Interventions target knowledge and behavior—usually for a specific condition
- Some interventions narrow the gap in self-management between low and higher literacy, but not all of them
- Most models of literacy and outcomes include knowledge and behavior prominently in the causal pathway



Baker DW. JGIM. 2006. 21:878-883.

A few pages later….

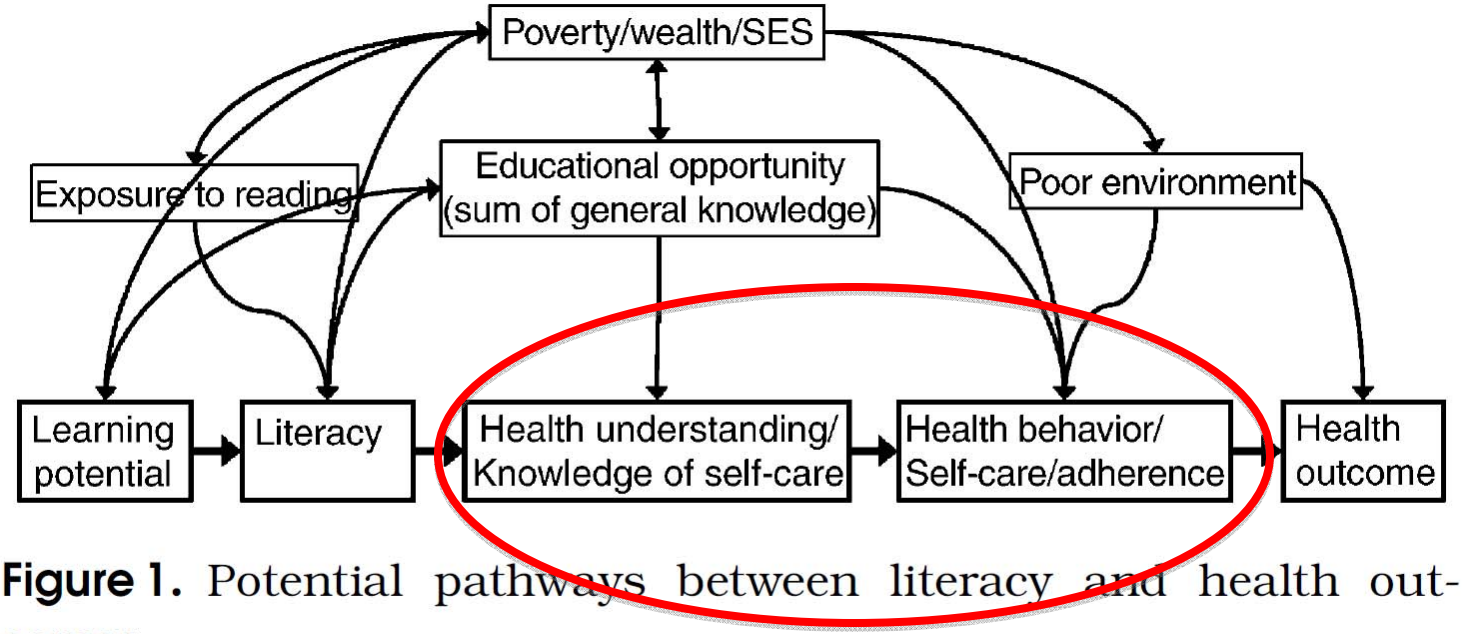
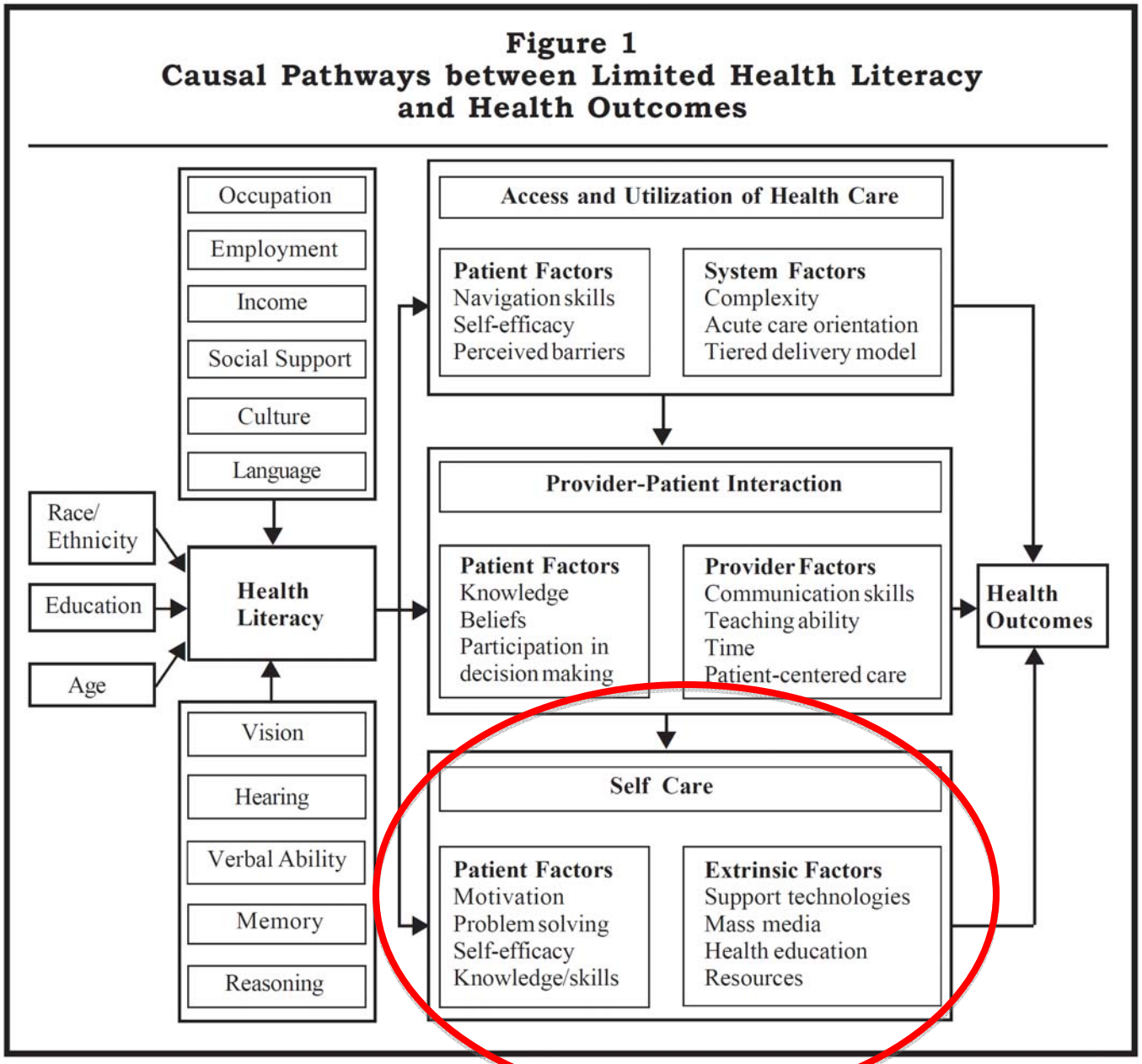


Figure 1. Potential pathways between literacy and health outcomes.

Pignone and DeWalt. JGIM 2006 Aug;21(8):896-7.



Paasche-Orlow and Wolf. AJHB. 2007. 31: S19-S26.

If the models are true, then…

- We should be able to demonstrate mediation in observational studies
- We should be able to reduce disparities in outcomes with educational interventions

- If the models are not true, then literacy may be a marker of something else
  - yet another measure of socioeconomic status

We do not have much empirical evidence on these models

- I will present 3 studies in which I have tried to address these questions.

- Chronic Obstructive Pulmonary Disease (COPD) –RCT
- Pediatric Oral Health –Cross-sectional
- Heart Failure --Cross-Sectional

Methodological Considerations

- How does study design influence how we interpret the results?

- What is the role of measurement in how we interpret the results?

COPD Requires Self-Management

Key self-management tasks

- Quit smoking
- Take medicine correctly (tricky)
- Exercise
- Avoid precipitants (viruses, environmental)
- Other things! (insurance, self-assessment)

Inhaled Medications

- Almost all pharmacotherapy for COPD is delivered by inhalation
- Both asthma and COPD patients generally have poor inhaler technique*
- Poor inhaler technique may result in ineffective medication delivery

*van Beerendonk et al. J Asthma. 1998; 35 (3): 273-9.
*Hesselink et al. Scand J Prim Health Care. 2001; 19 (4): 255-60.
*Williams et al. Chest 1998, 114(4):1008-1015

COPD Randomized Controlled Trial

- Educational intervention to improve inhaler technique
- Baseline assessment of health status and inhaler use
- Administer educational intervention
  - placebo inhalers to teach and then practice until mastered
- Follow up evaluation 2-4 weeks later

Metered Dose Inhaler

1. Remove cap
2. Shake the inhaler
3. Breathe out completely
4. Place inhaler 1-2 inches away from mouth OR in mouth and close lips tightly around mouthpiece
5. Activate the MDI at the start of inhalation
6. Slowly and deeply breathe in
7. Hold breath for at least 10 seconds
8. Wait at least 1 minute before repeating steps 3 through 8

	Overall	Intervention	Usual Care
N	99	67	32
Mean age (range)	63 (43-84)	63 (43-84)	63 (44-83)
African American (%)	29	30	28
Caucasian (%)	69	67	72
Female (%)	65	64	66
Insured (%)	93	91	97
Annual household income			
% < $15,000	51	52	50
% $15,000 to $29,999	26	27	22
% $30,000 or greater	23	21	28
Education			
% ≤11th grade	31	27	40
% Hs grad or GED	29	30	28
% Some college or >	39	42	31
Low Health Literacy (%) (Marginal/Inadequate TOFHLA)	36	37	33
SGRQ score mean (SD), range¶	53 (16), 19-88	54 (16)	49 (15)
FEV1 % Predicted, mean (SD)	55 (20)	54 (20)	58 (17)
Use Oxygen (%)	26	30	19

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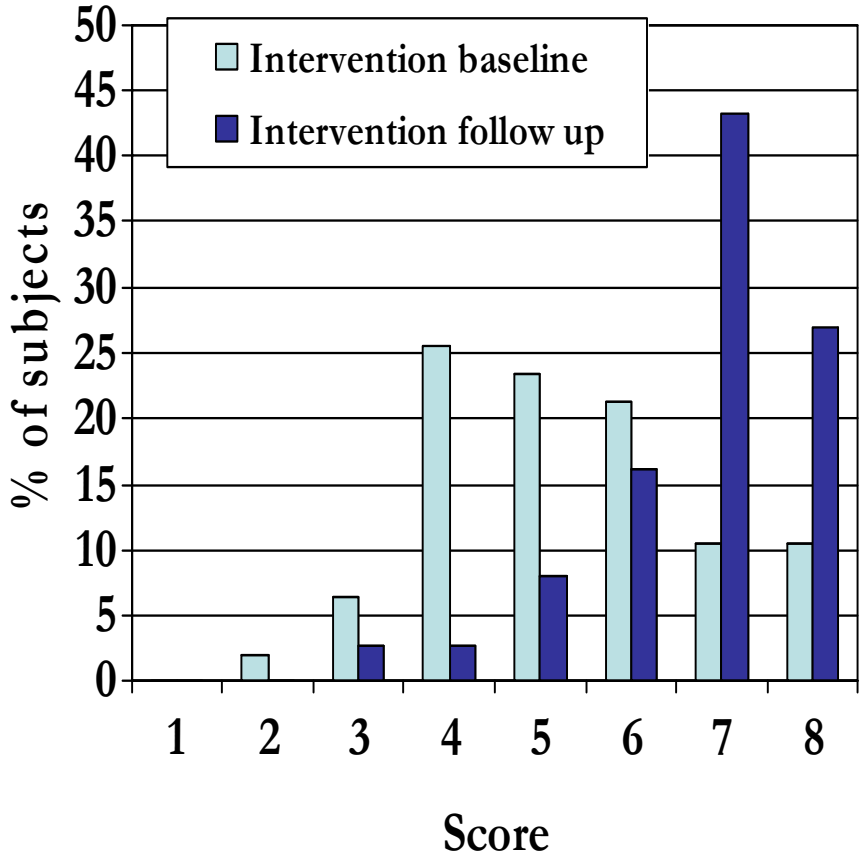
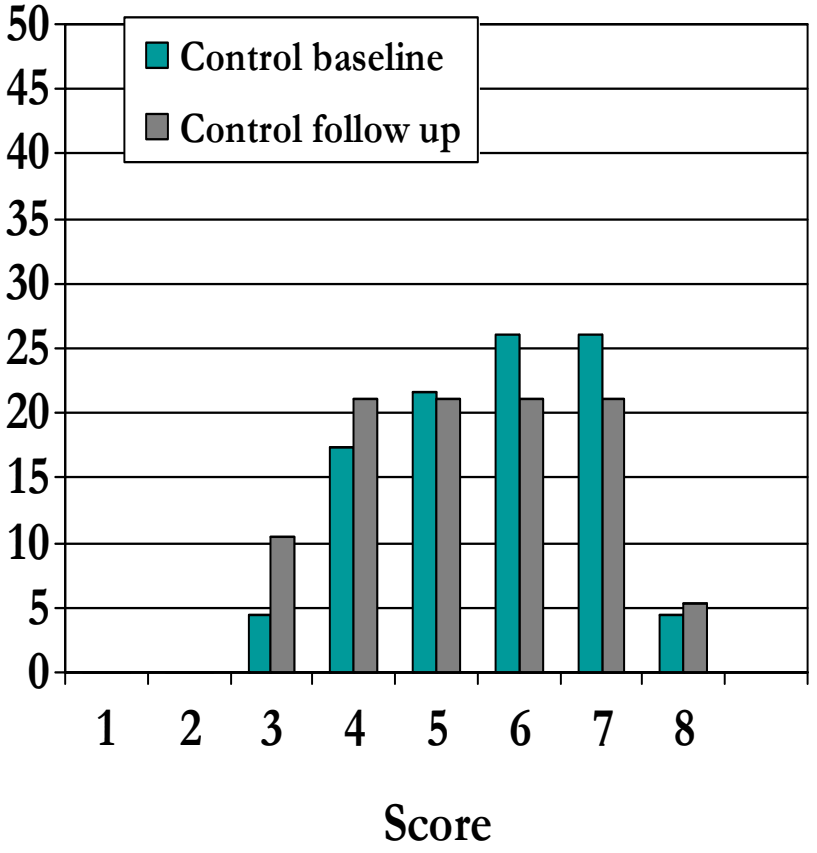
MDI technique score





Inhaler Use Scores

Inhaler	Usual Care (n=32)			Intervention (n=67)			Difference in Mean Change (95% CI)	p value
	Baseline Score	F/U Score	Mean Change	Baseline Score	F/U Score	Mean Change		
Overall	5.6	5.2	-0.5	5.2	6.7	1.6	**2.1 (1.1, 3.0)**	<0.001
Low Literacy	5.2	4	-1.0	4.8	6.3	1.8	2.8 (0.6, 4.9)	0.015
Higher Literacy	5.8	5.5	-0.3	5.4	6.9	1.5	1.8 (0.7, 2.9)	0.001

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COPD Summary

- People with lower literacy have lower baseline knowledge/behavior scores
- Educational program improves knowledge and behavior for all literacy levels
- Improvement is greater for low literacy (closing the gap)
- This is how it should work….if our hypothesis is correct

Preventing Dental Caries Requires Self-Management

Key Self-Management Tasks

- Brush daily
- Avoid bottles/sippy cups at bedtime
- Use fluoride toothpaste

Impact of Caregiver Literacy on Children's Oral Health Outcomes

- Cross-sectional study of children’s oral health and parental literacy (N=106)
- Children $\leq$ 6 y/o
- Parents complete Rapid Estimate of Adult Literacy in Dentistry-30
- Clinical assessment of caries
- Oral Health Knowledge
- Oral Health Behaviors

Oral Health Measures

- Clinical assessment of caries
  - Highly trained examiners
- Oral Health Knowledge
  - Drinking juice from a "sippy" cup throughout the day can cause cavities
- Oral Health Behaviors
  - Do you put your child to bed with a bottle?

	Frequency (N)	Percent (%)
Child's Sex		
Male	63	59.4
Female	43	40.6
Child's Race		
White	56	52.8
Black/African American	24	22.6
Hispanic/Latina	11	10.4
Other	15	14.2
Caregiver Relationship		
Mother	90	85.7
Father	10	9.5
Grandfather	4	3.8
Other	1	1.0
Caregiver Education Level		
Less than High School	8	8.0
High School or GED	20	20.0
Some College or Technical Degree	39	39.0
College Degree or More	33	33.0
Household Income		
$30,000 or less	46	45.5
$30,000-50,000	27	26.7
More than $50,000	28	27.8

Miller et al. Pediatrics 2010. 126:107-114.

Results

- Parental literacy NOT related to oral health knowledge (Spearman rho 0.13, p=0.16)
- Parental literacy NOT related to oral health behaviors
- Parental literacy STRONGLY related to presence of severe tooth disease even after adjusting for race and income
  - OR 1.14 (1.05, 1.25) for every point on READ

Miller et al. Pediatrics 2010. 126:107-114.

Oral Health Behavior

1. Do you put your child to bed with a bottle? Y/N

2. Do you brush or clean your child's teeth or gums every day? Y/N

3. Do you use toothpaste when brushing your child's teeth? Y/N

Hmmm…

- Literacy not related to knowledge or behavior

Oral Health Behavior

1. Do you put your child to bed with a bottle? Y/N

2. Do you brush or clean your child's teeth or gums every day? Y/N

1. Do you use toothpaste when brushing your child's teeth? Y/N

1. How many times did your child go to bed with a bottle or sippy cup?

every night
5-6 nights
2-4 nights
1 night
used to go to bed with a bottle/sippy cup but stopped
never goes to bed with a bottle

2. How often did you (or another adult) help your child brush their gums or teeth?

my child does not need my help brushing
at least 2 times a day
once a day
a few times a week
once a week

3. In the past, what have you used to clean your child's teeth and/or gums? (check all that apply)

washcloth
toothbrush
toothpaste with fluoride
toothpaste without fluoride
mouthwash
chewing gum

Oral Health Summary

- Knowledge and behaviors don’t explain literacy to health connection….
- Is it a measurement problem (bias or just the wrong domains)?

- Do we need so show knowledge is a mediator to believe we can design effective interventions that target literacy related barriers?

Heart Failure Requires Self-Management

Key Self-Management Tasks

- Avoid Salt
- Take medicines correctly
- Exercise
- Self-monitor symptoms and weight

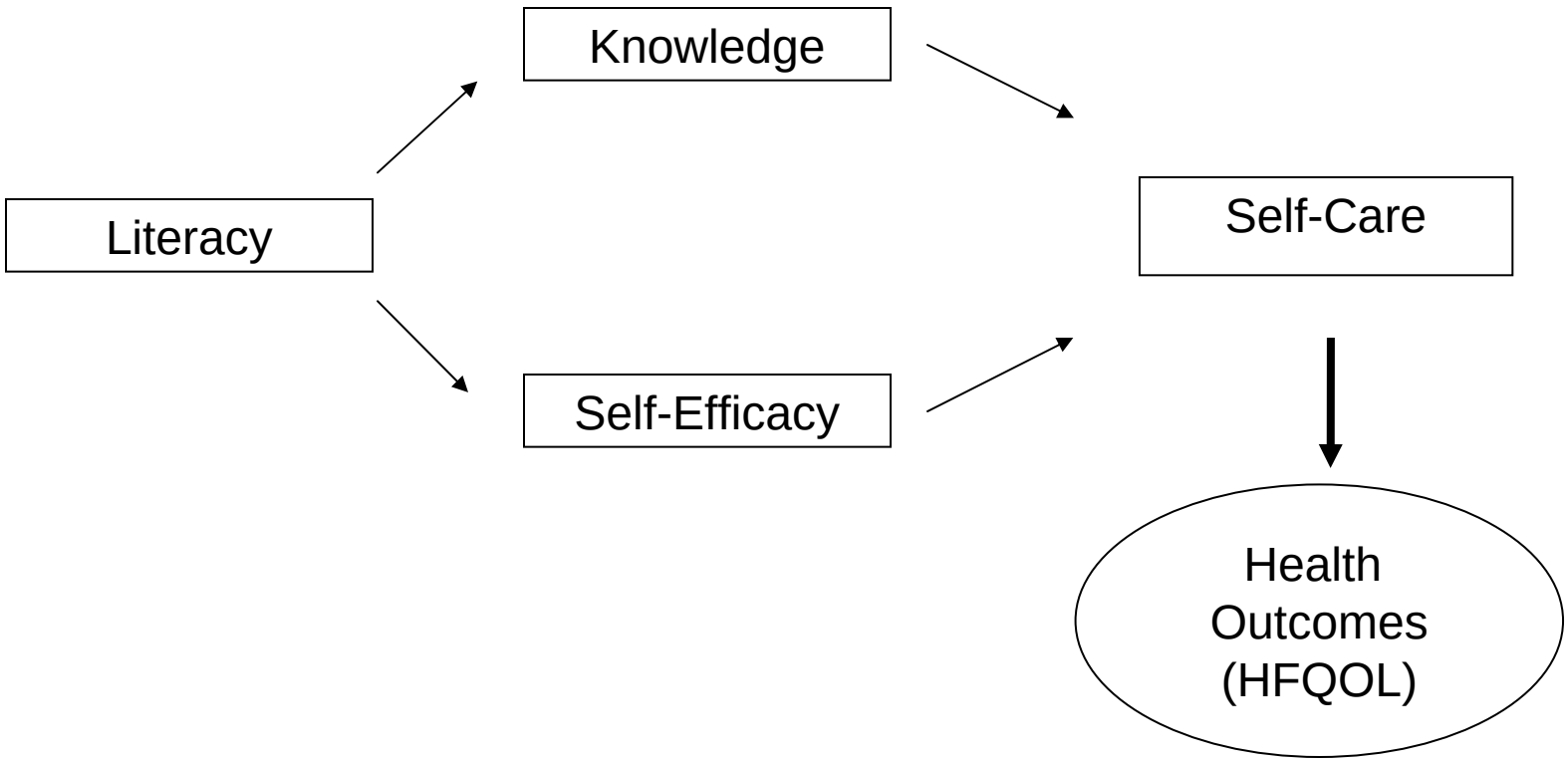
Cross-sectional Study of Patients with Heart Failure

- Enrolled 605 patients with heart failure for randomized controlled trial
- All patients had to be symptomatic in the past 6 months
- Enrolled at 4 sites (UNC, UCLA, Northwestern, San Francisco General Hospital)

Measurement

- Short Test of Functional Health Literacy in Adults
- General HF knowledge
- Salt-related knowledge
- HF-related self-efficacy
- Self-care behaviors
- HF-related quality of life (HFQOL)

Simple Model for Intervention



Bivariate Analysis Results

	Adequate Literacy	Inadequate Literacy	Unadjusted Difference		Adjusted* Difference	
HFQOL	63.9±22.1	55.4±20.6	8.5**	(12.2, 4.9)	7.2**	(11.1,2.9)
HF Knowledge	6.6±1.7	5.5±1.8	1.1**	(1.4,0.8)	0.6**	(1.0,0.3)
Salt Knowledge	8.2±1.4	7.5±1.8	0.8**	(1.0,0.5)	0.5**	(0.9,0.2)
Self-Care Behavior	5.3±2.0	4.2±1.7	1.0**	(1.4,0.7)	0.6**	(1.0,0.2)
Self-Efficacy Scale	5.0±2.8	4.1±2.9	0.9**	(1.4,0.5)	1.0**	(1.6,0.4)

*Adjusted for race/ethnicity, age, insurance coverage, previously uninsured, and relative socioeconomic position

**significant at 1%

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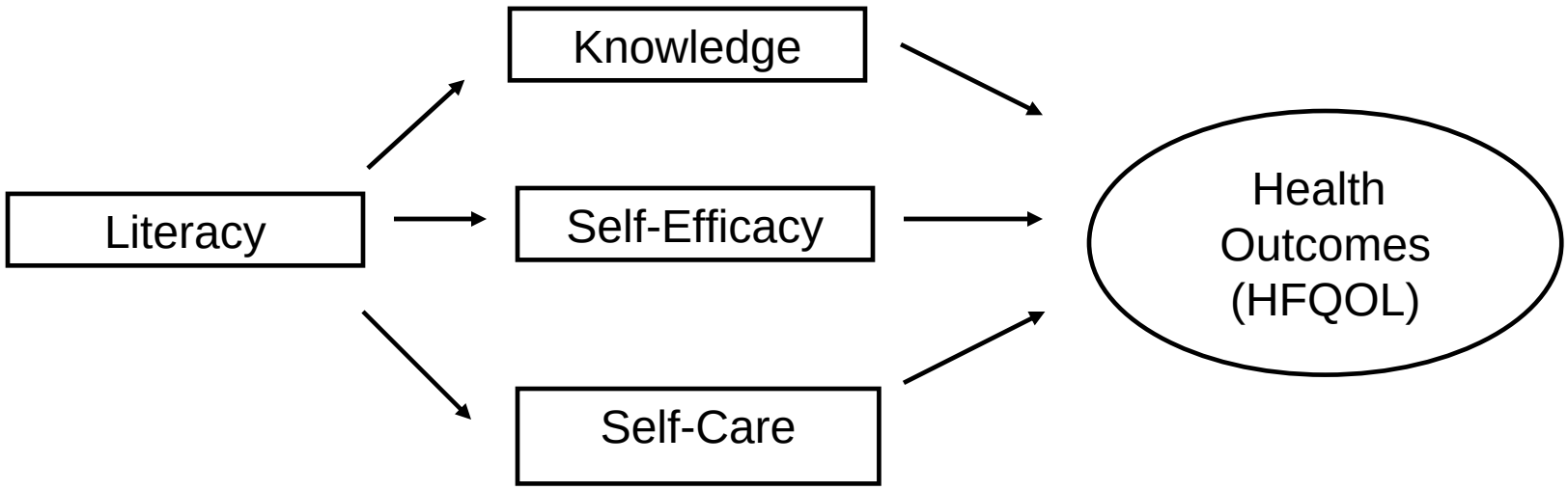
Simpler Model for Analysis



Mediation Analyses (Baron and Kenny)

Dependent Variable: HFQOL	**Model 1**	**Model 2**	**Estimated indirect effects**
Low literacy	-7.20** (-11.30,-3.10)	-6.70** (-10.86,-2.55)	
Number right of general HF knowledge		-1.34* (-2.38,-0.30)	0.85* (0.03,1.67)
Self-efficacy		1.06** (0.45,1.67)	-0.57* (-1.05,-0.10)
Number right on salt questions		0.41 (-0.70,1.52)	-0.40 (-1.56,0.75)
Self care behaviors		0.13 (-0.84,1.10)	-0.08 (-0.68,0.52)
Joint test of mediating variables: F(4,567)		4.65 (p=.0011)	

N=585. **: significant at 1% *: significant at 5%
All results also adjusted for race/ethnicity, age, insurance coverage, previously uninsured, and subjective socioeconomic position

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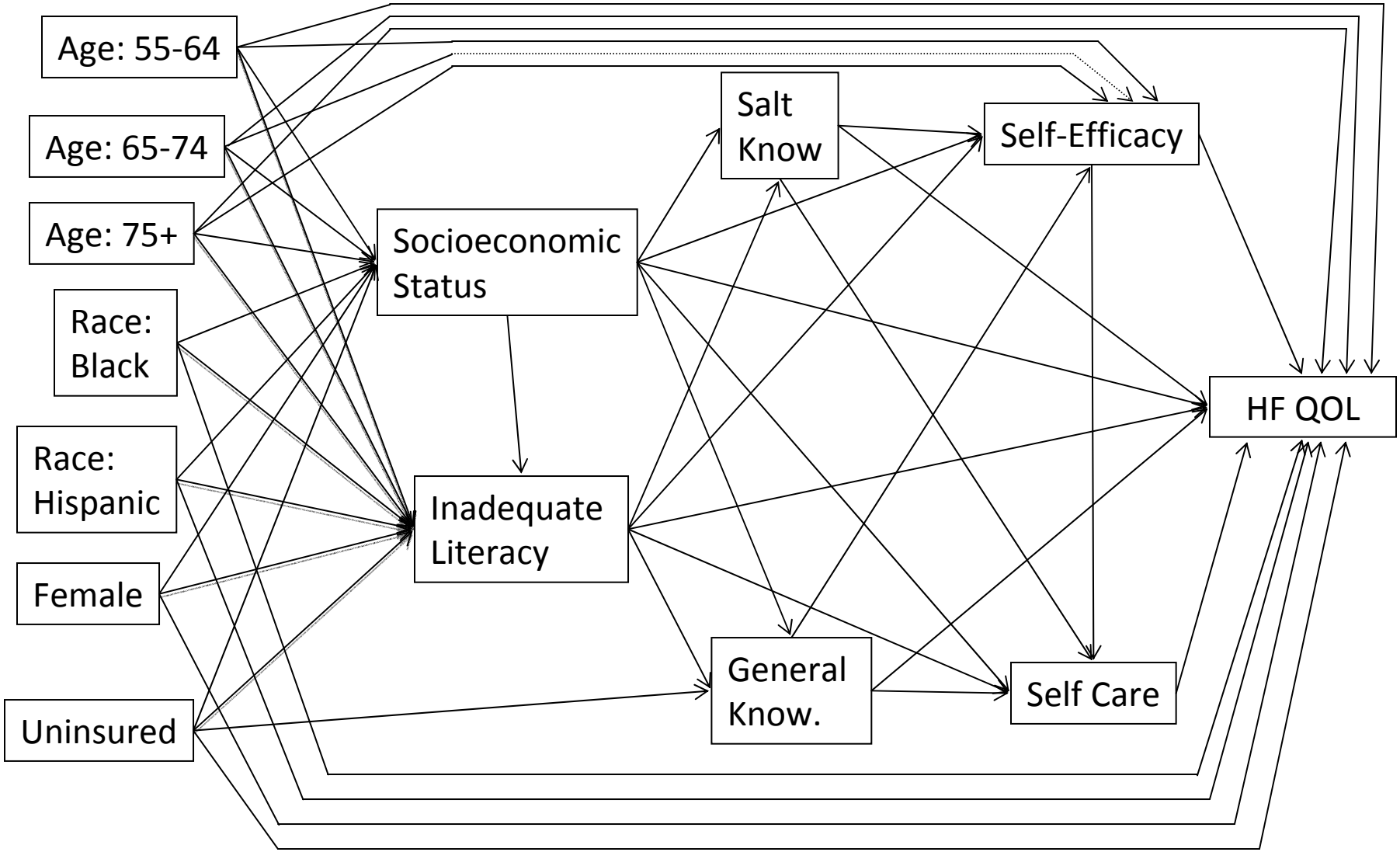
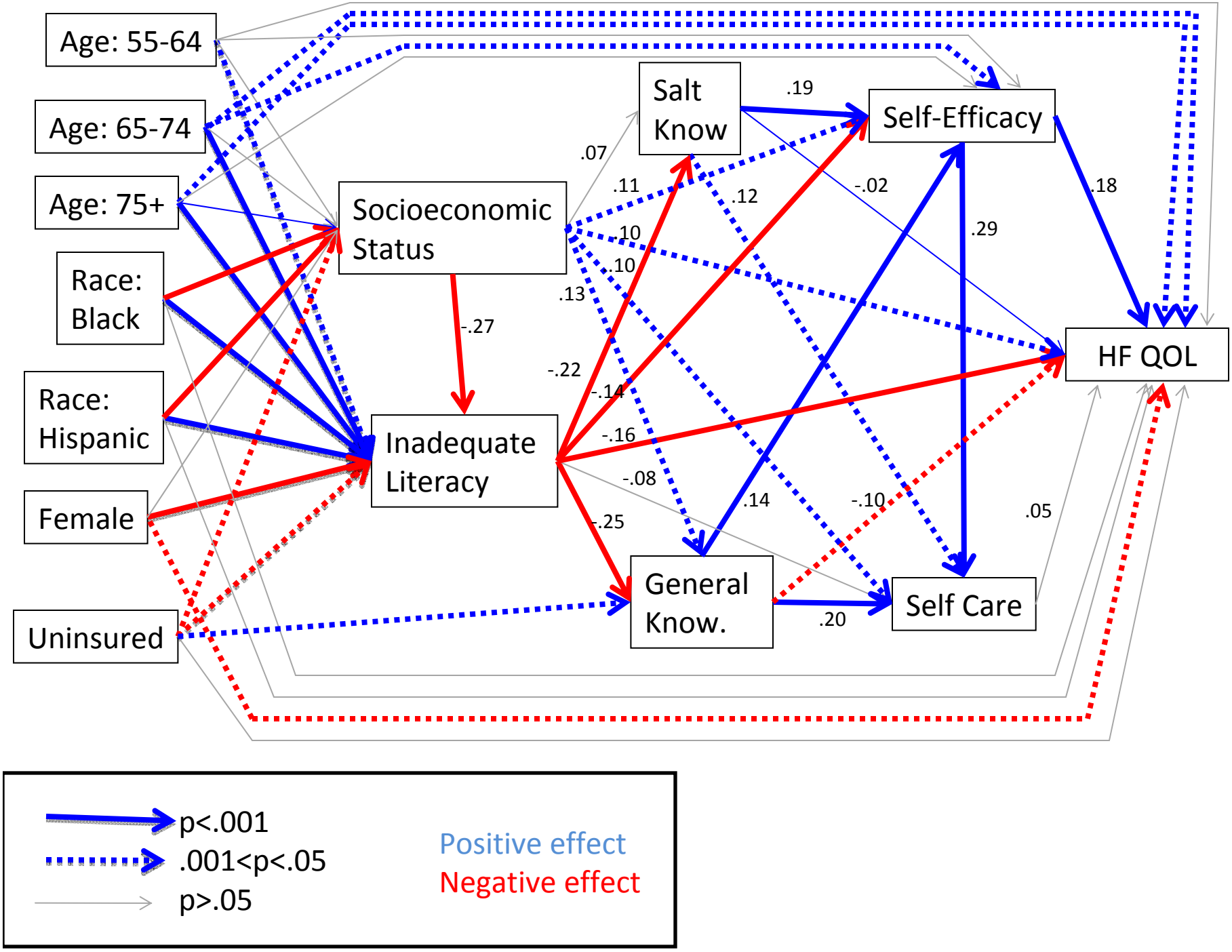
Another type of analysis: Structural Equation Modeling




Age: 55-64
Age: 65-74
Age: 75+
Race: Black
Race: Hispanic
Female
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Salt Know
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Self-Efficacy
Self Care
HF QOL
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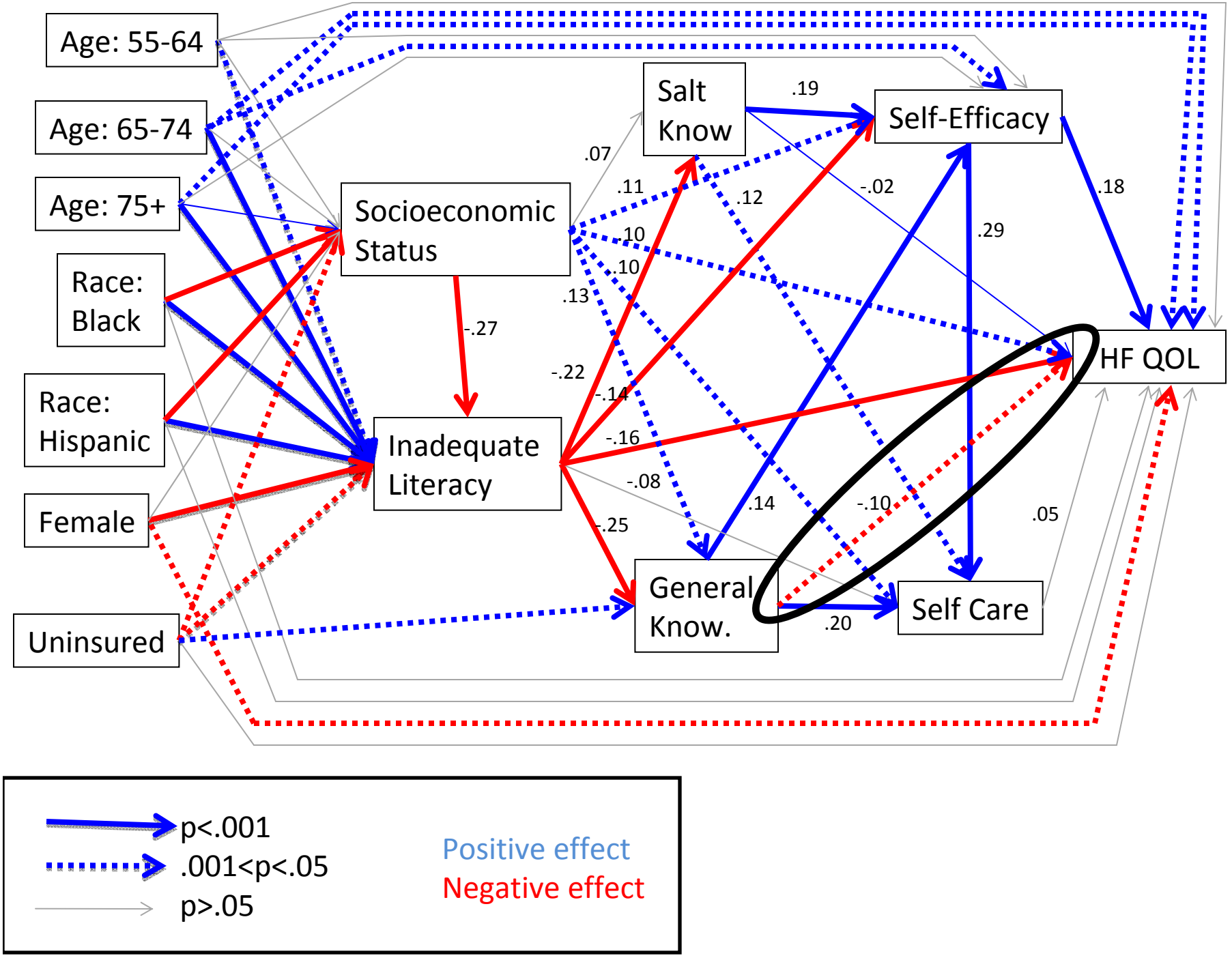
.20
p<.001
.001<p<.05
p>.05
Positive effect
Negative effect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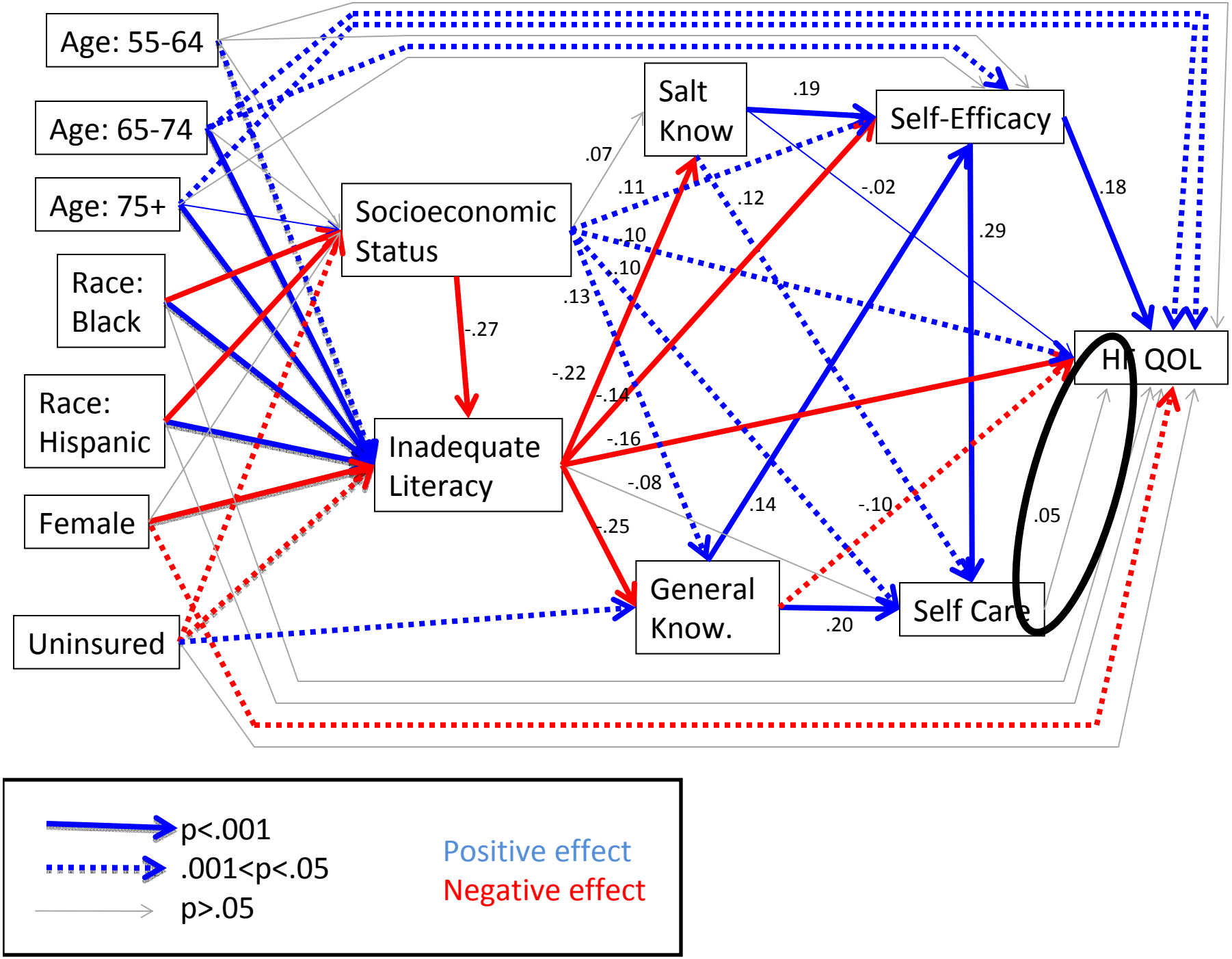
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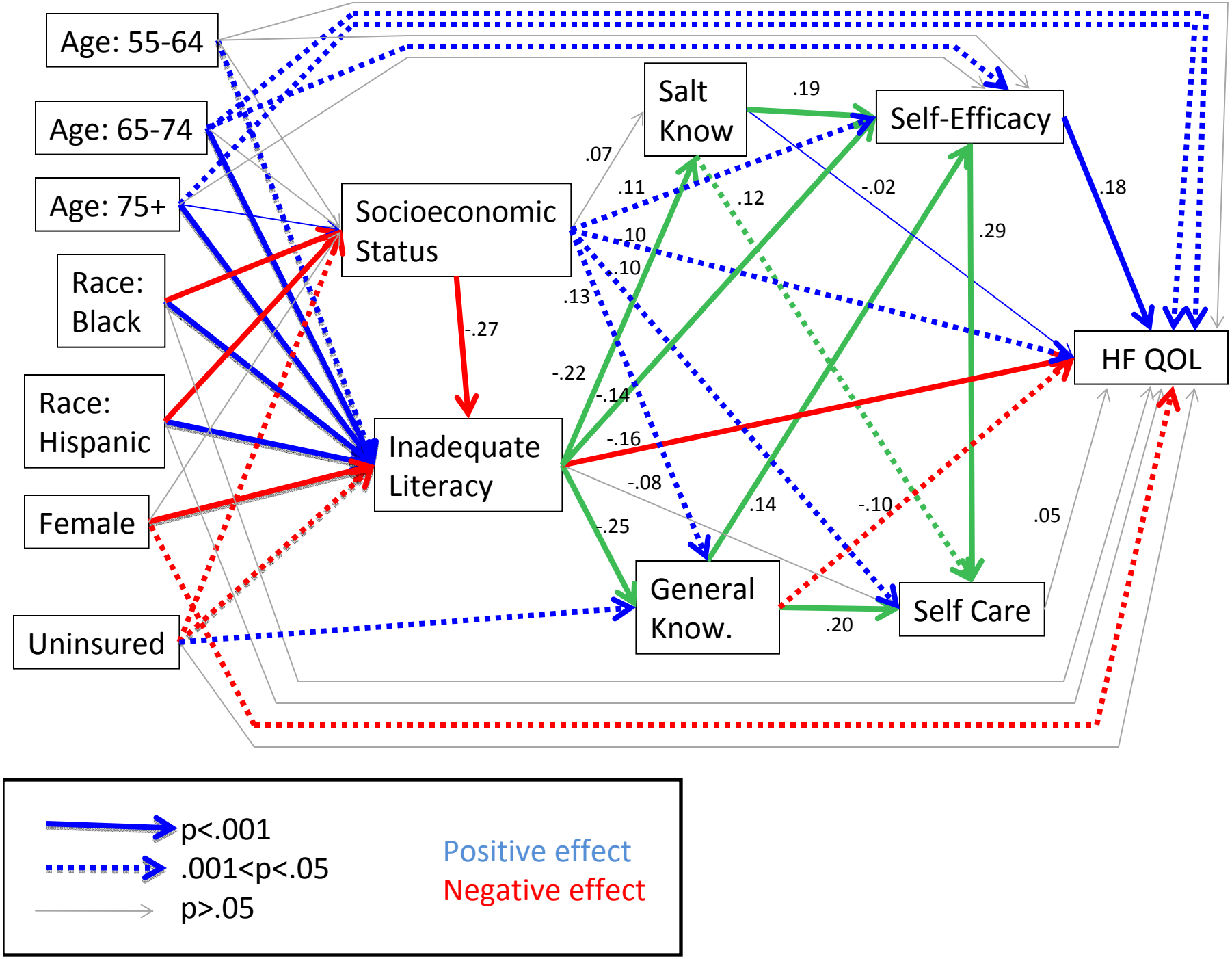
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What Does SEM Offer?

- Perhaps a richer view of the inter-relationships between the variables
- No major differing conclusions from traditional mediation analysis
- Does confirm that literacy → self-care is mediated by knowledge and self-efficacy

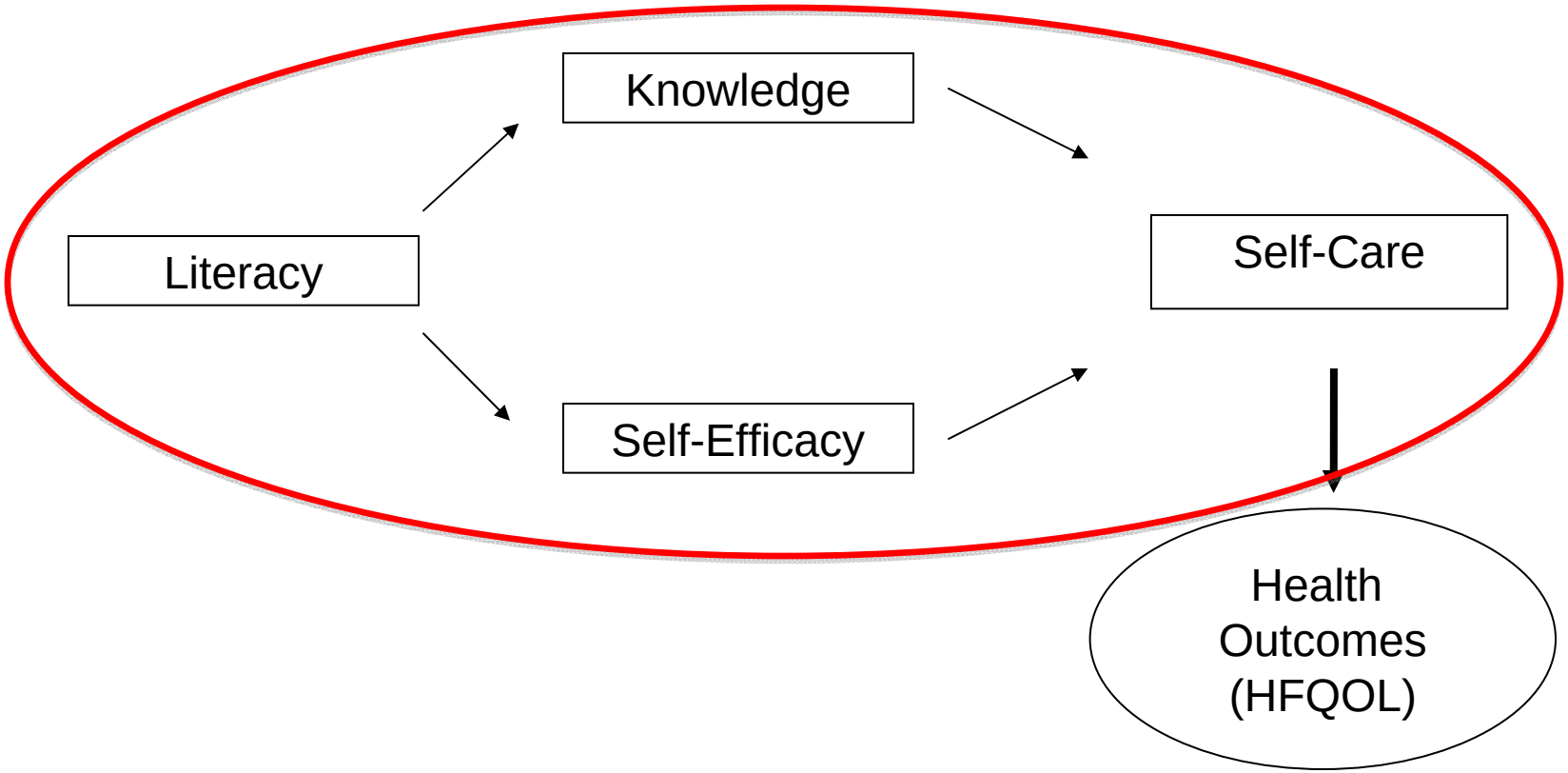
So, What Happened in This Study?

- People with worse HFQOL may have been more exposed to HF education via hospitalizations or other health care interaction (cross-sectional study design problem)
- We are not measuring the right knowledge and behaviors….
- Interesting how we are comfortable making these explanations when the data don't fit our models

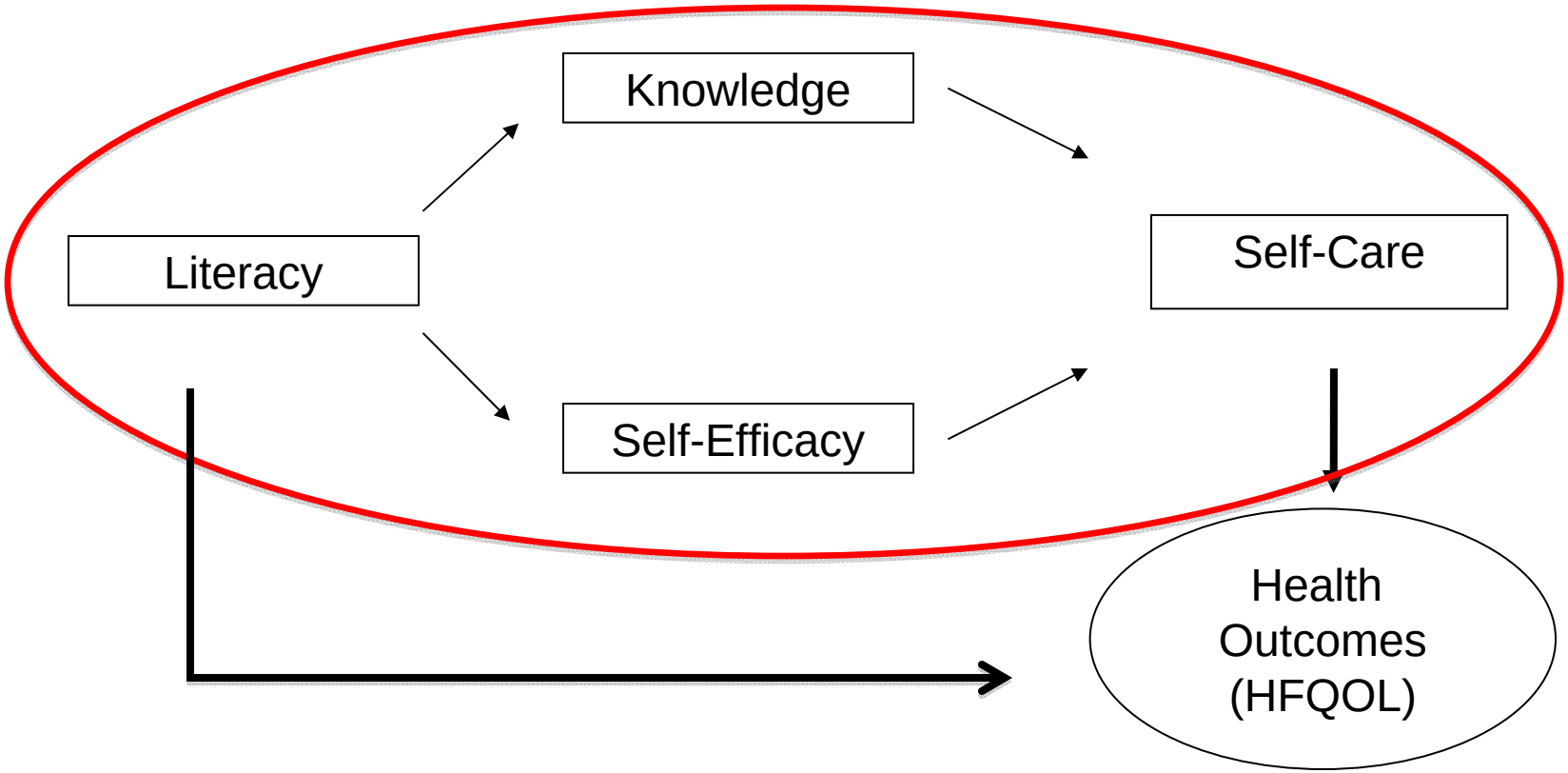
Concerns about Literacy and Self-Management

- Maybe our view of self-management is too narrow (very disease focused)
- Maybe our measures of the mediating variables are wrong
- Maybe literacy has other pathways to health outcomes

This Part *May* Work



But it is Not the *Whole* Story



Summary

- Some educational programs can narrow disparities in knowledge/self-management
- Empirical data on the path from literacy to outcomes is often lacking
- Maybe literacy is exerting a more global effect on outcomes via many paths
- Our interventions may need a broader scope than focused education on a disease

Thanks to Study Teams

Heart Failure
Michael Pignone
Darren A DeWalt
Victoria Hawk
Mark Holmes
Brian Erman
Morris Weinberger
Kim Broucksou
Aurelia Macabasco-O'Connell
David W Baker
Bernice Ruo
Kathy L. Grady
Dean Schillinger
Kirsten Bibbins-Domingo

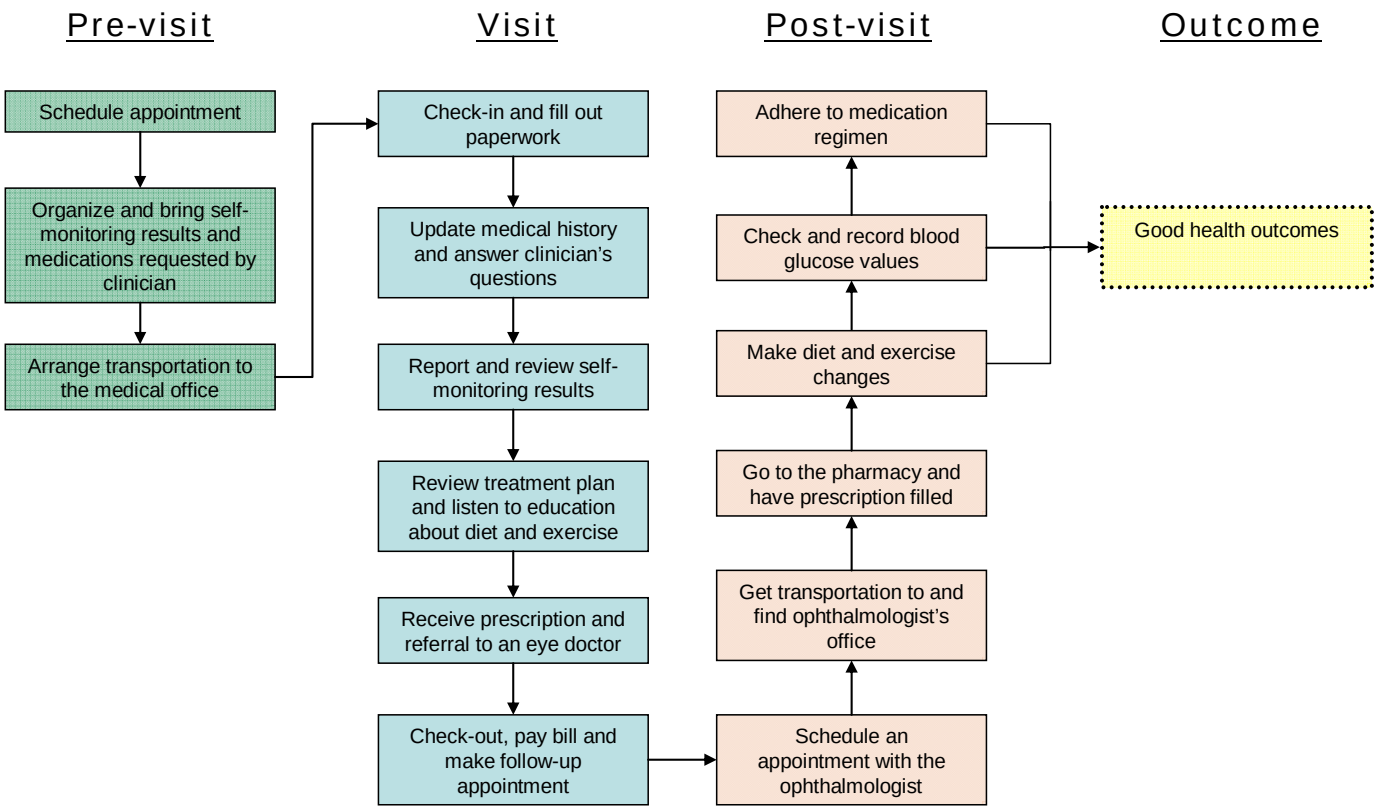
COPD
Dan Jonas
Katie Kiser
Michael Gilchrest
Zach Warner
Betsy Bryant Shilliday
Kelli Scanlon

Pediatric Oral Health
Jessica Lee
Liz Miller
William Vann
Lauren Sanzone

End

What are all the things a patient with low literacy needs to do?

Patient Tasks for Diabetes Follow-up Visit

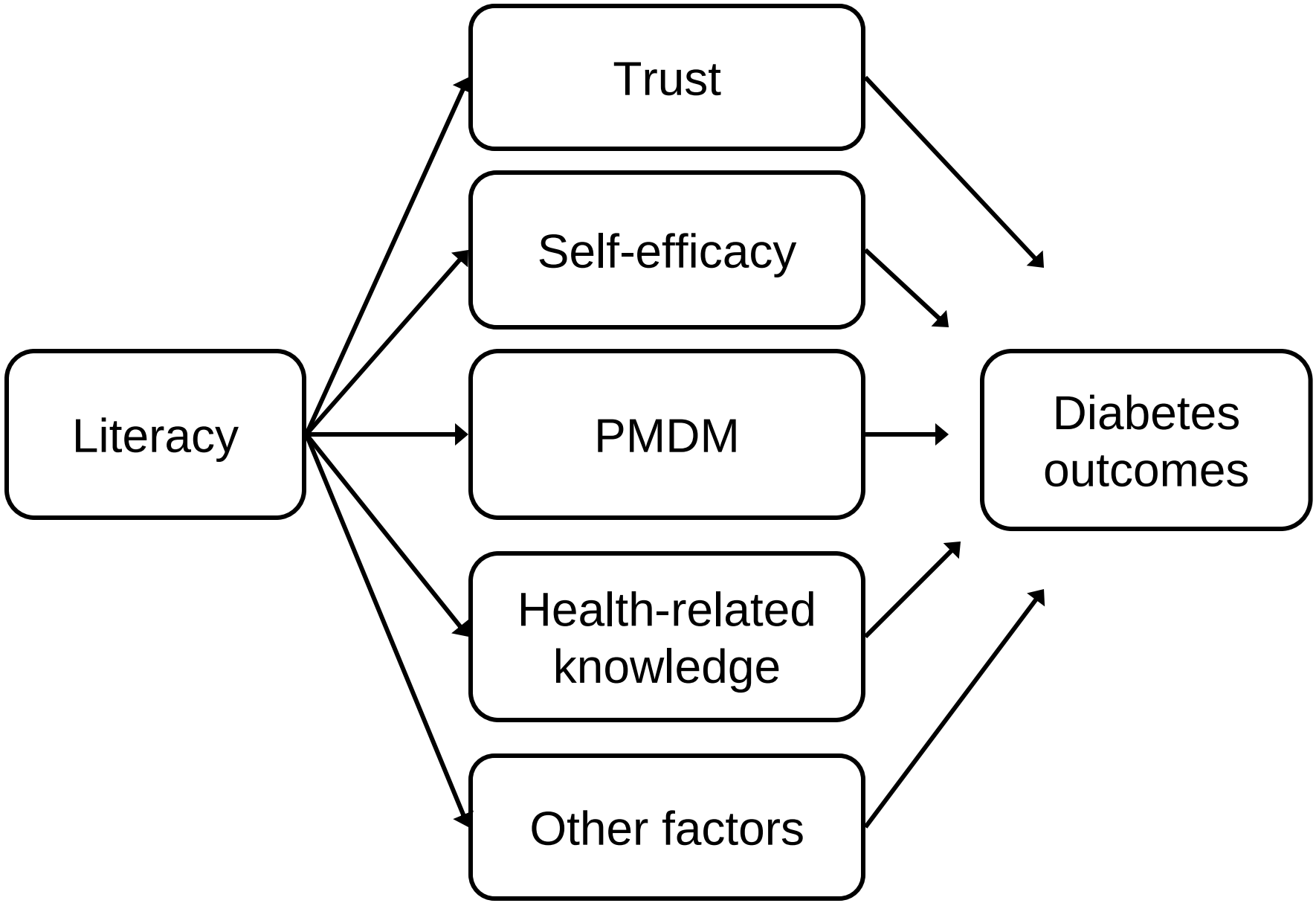


Diabetes Requires Self-Management

Diabetes Cross-Sectional Study

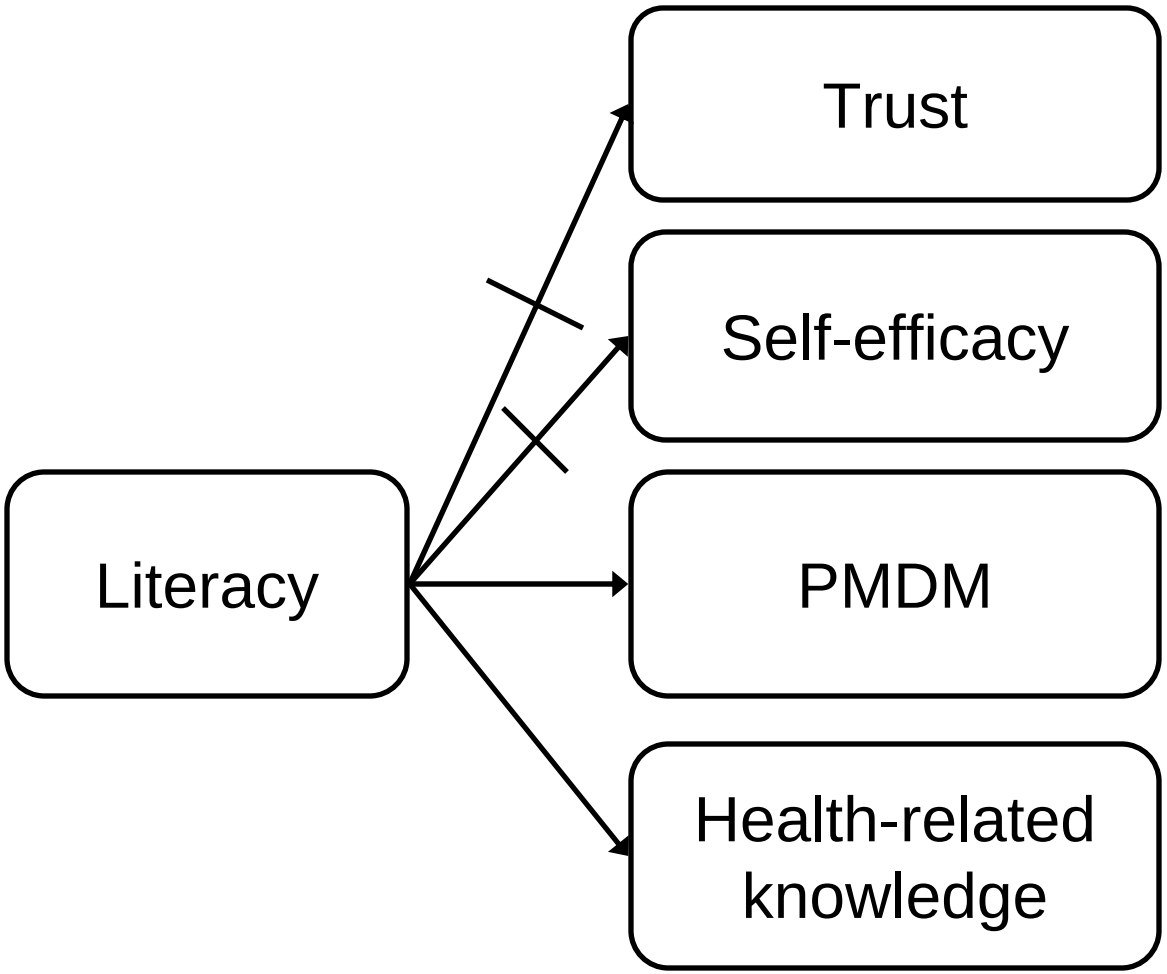
- Enrolled 268 patients with type 2 diabetes from UNC general medicine practice
- Examined most recent A1C and used questionnaire to measure
  - Knowledge
  - Self-efficacy
  - Trust
  - Desire to participate in medical decision-making

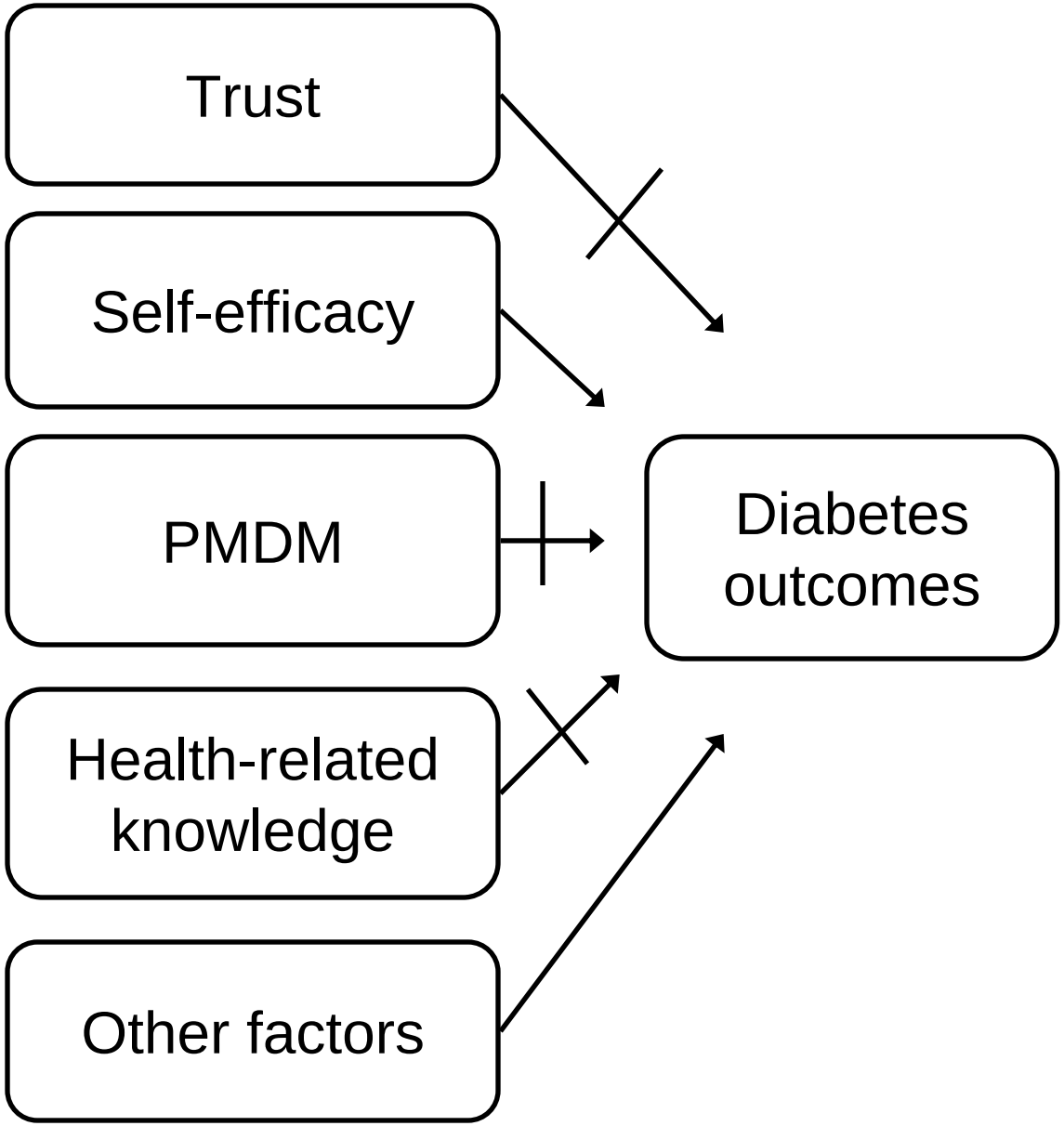
DeWalt et al. 2007. AJHB 31: S27-35


Trust
Self-efficacy
Literacy
PMDM
Diabetes outcomes
Health-related knowledge
Other factors

No Relationship between Literacy and A1C

	Higher Literacy	Low Literacy	Difference	CI	P value
Mean A1C	7.6	7.4	-0.2	-0.7, 0.3	0.4


Trust
Self-efficacy
Literacy
PMDM
Health-related knowledge


Trust
Self-efficacy
PMDM
Health-related knowledge
Other factors
Diabetes outcomes

Diabetes Study Summary

- Literacy related to knowledge
- Literacy related to desire to participate in medical decision making
- No mediation identified…..

- Knowledge and participation in decision making may be more related to outcomes for other diseases