

# Health Literacy 101

## Defining The Problem and What We Can Do About It

Darren DeWalt, MD, MPH  
& Michael Pignone, MD, MPH  
University of North Carolina-Chapel Hill  
Department of Medicine

# Issues

- Defining health literacy
- Epidemiology of literacy and its relationship to health
- Practical interventions

*“As a former nurse, trauma surgeon, and public health director [I realized] there was a wall between us and the people we were trying to serve.*

*Health care professionals do not recognize that patients do not understand the health information we are trying to communicate.*

*We must close the gap between what health care professionals know and what the rest of America understands.”*



**Dr. Richard Carmona,  
U.S. Surgeon General 2002-2006**



# Health Literacy

“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

Healthy People 2010



# Epidemiology of Literacy



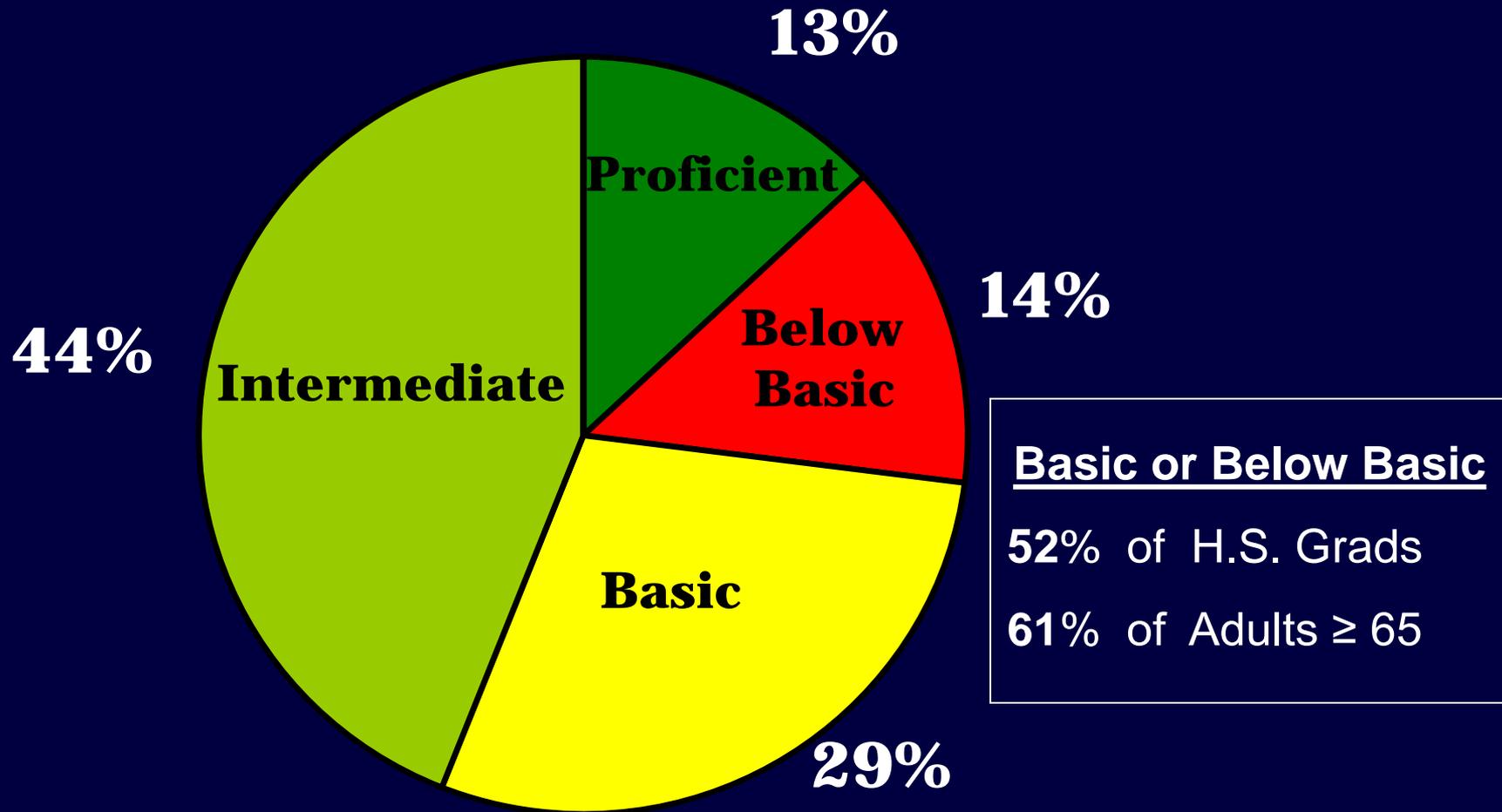
# National Assessment of Adult Literacy (NAAL)\*

n = 19,714

- Most up to date portrait of literacy in U.S.
- Scored on 4 levels
- Levels 1 and 2 cannot:
  - Use a bus schedule or bar graph
  - Explain the difference in two types of employee benefits
  - Write a simple letter explaining an error on a bill

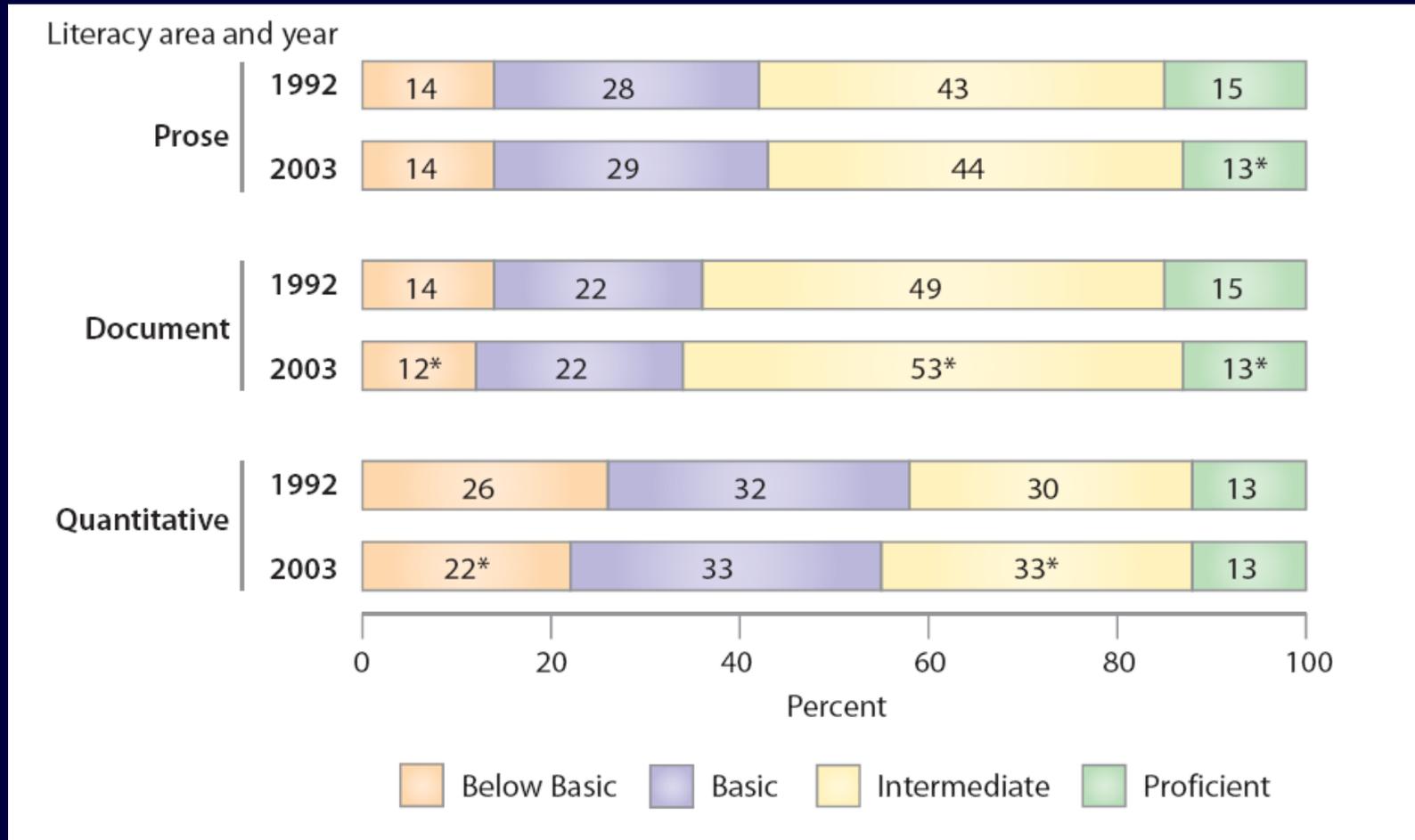
National Center for Educational Statistics, U.S. Department of Education

# 2003 National Assessment of Adult Literacy



*93 Million Adults have Basic or Below Basic Literacy*

# Not Much Improvement in 10 Years

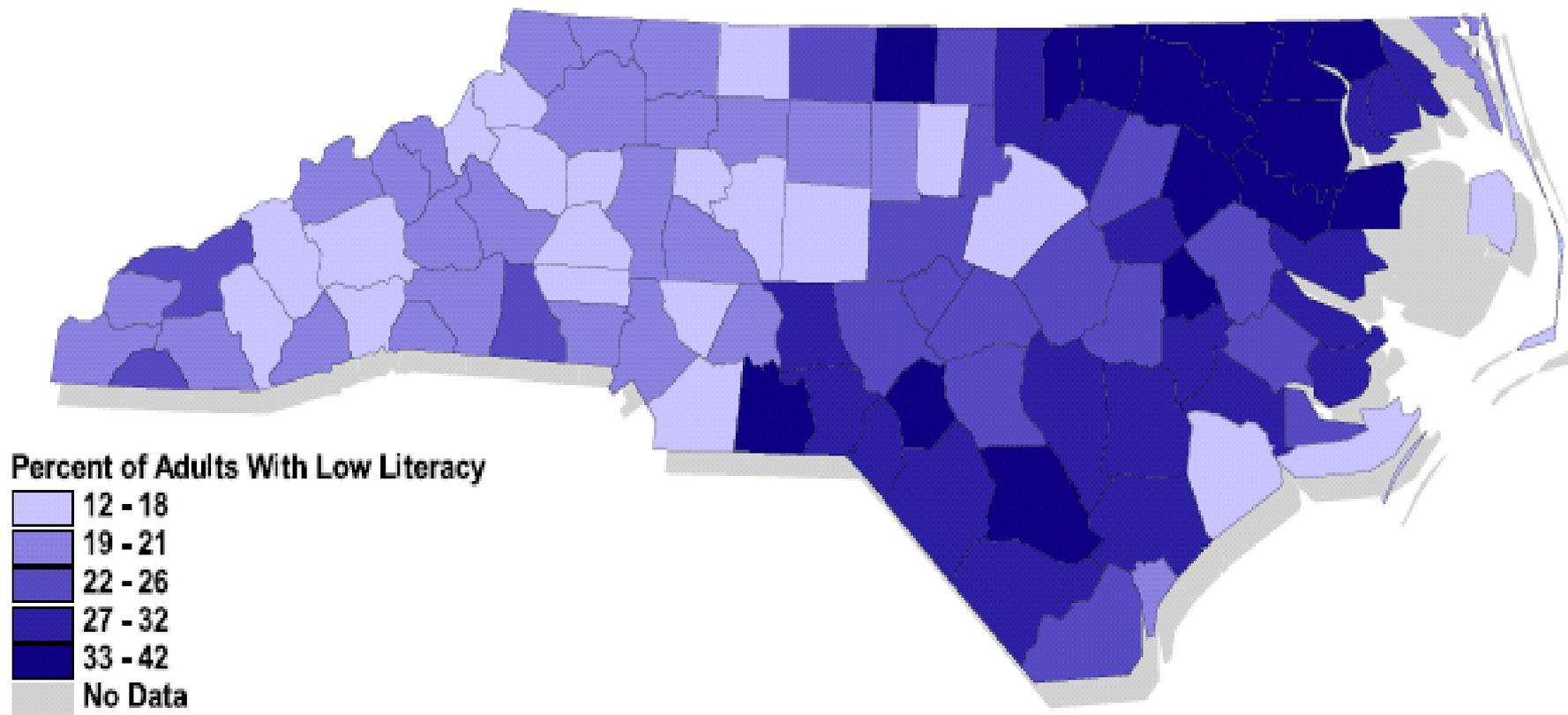


Kutner et al. National Assessment of Adult Literacy. 2005

# What about NC?

- Estimates from 1992
- Level 1 or 2 (basic or below basic literacy): 52%  
[National 50%]
- Because of the expansion of immigrant and retired populations since 1992, this likely underestimates the percentage reading at basic or below basic.

# Percent Of Adults With Low Literacy

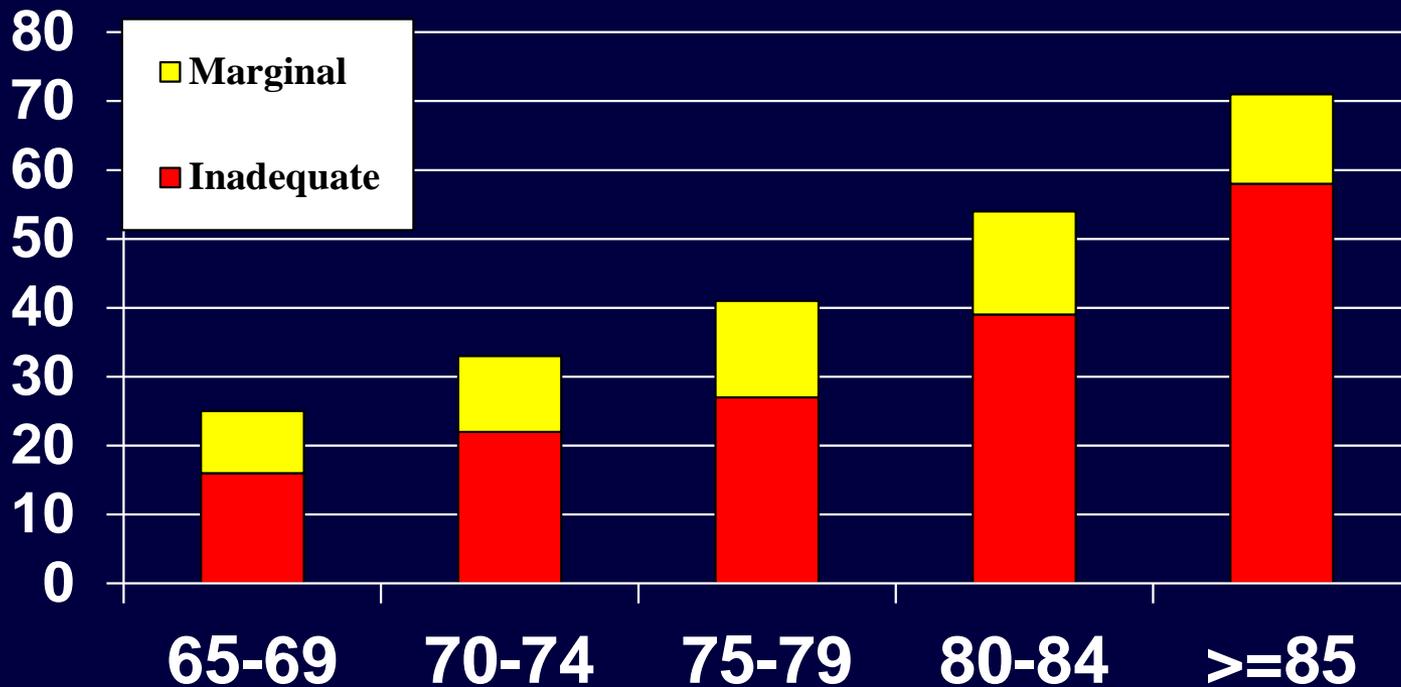


Source: Reder, Stephen. The State of Literacy in America. <http://www.nifl.gov/reders/reder.htm>.

Map Produced by North Carolina Institute of Medicine.

Estimates not available for counties with population below 5000.

# Inadequate Literacy Increases with Age



# Literacy and Spanish Language

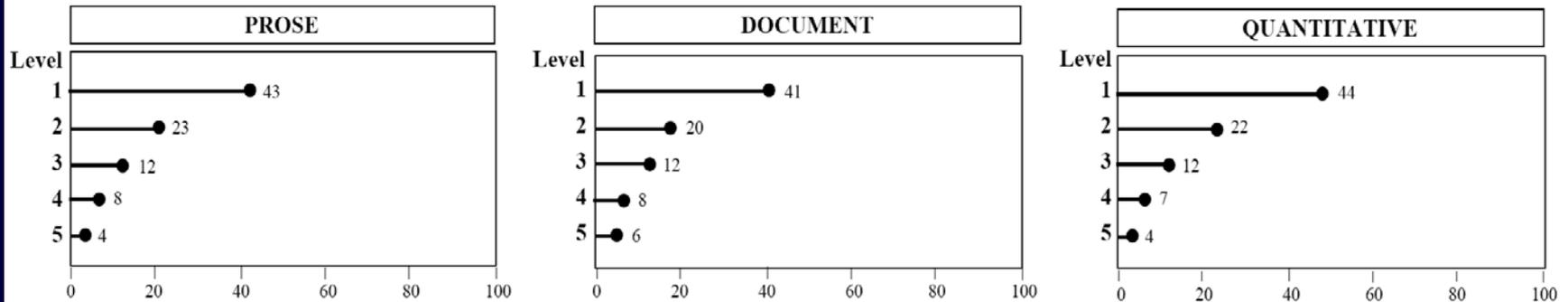
- 11 million US residents do not speak English well or at all
- 8 million of these speak Spanish

## Test of Functional Health Literacy in Adults at two Public Hospitals

Language	Percent Low Literacy (in preferred language)
English	35%
Spanish	62%

# Literacy and Poverty

Percentages of Adults in Poverty, by Literacy Level



Percentage in Each Level in Poverty

Note: Adults in poverty are those who are either poor or near poor.

<b>Level 1</b>	0 to 225
<b>Level 2</b>	226 to 275
<b>Level 3</b>	276 to 325
<b>Level 4</b>	326 to 375
<b>Level 5</b>	376 to 500

Source: U.S. Department of Education, National Center for Education Statistics, National Adult Literacy Survey, 1992.

# Sample Question

Seventy-eight percent of what specific group agree that their school does a good job of encouraging parental involvement in educational areas?

## % Correct

36% All Adults

0% < Basic

4% Basic

### Parents and Teachers Evaluate Parental Involvement at Their School

*Do you agree or disagree that...?*

	Total	Level of School		
		Elementary	Junior High	High School
<i>percent agreeing</i>				
Our school does a good job of encouraging parental involvement in sports, arts, and other nonsubject areas				

Parents	77	76	74	79
Teachers	77	73	77	85

Our school does a good job of encouraging parental involvement in educational areas

Parents	73	82	71	64
Teachers	80	84	78	70

Our school only contacts parents when there is a problem with their child

Parents	55	46	62	63
Teachers	23	18	22	33

Our school does not give parents the opportunity for any meaningful roles

Parents	22	18	22	28
Teachers	8	8	12	7

Source: The Metropolitan Life Survey of the American Teacher, 1987







# Relationship Between Literacy and Health Outcomes

# Outcomes Associated with Literacy

## Health Outcomes/Health Services

- General health status
- Hospitalization
- Prostate cancer stage
- Depression
- Asthma
- Diabetes control
- HIV control
- Mammography
- Pap smear
- Pneumococcal immunization
- Influenza immunization
- STD screening
- Cost

## Behaviors Only

- Substance abuse
- Breastfeeding
- Behavioral problems
- Adherence to medication
- Smoking

## Knowledge Only

- Birth control knowledge
- Cervical cancer screening
- Emergency department instructions
- Asthma knowledge
- Hypertension knowledge

DeWalt, et al. JGIM 2004;19:1228-1239

# Patient Safety

## *Medication error: most common medical mistake*

- 90 million Americans have trouble understanding & acting on health information
- Unfamiliar/complex text most difficult to read
- 3 billion Rx written a year
- Pharmacist/physician time is limited
- Elderly fill 30 Rx/year, see 8 physicians



# “How would you take this medicine?”

395 primary care patients in 3 states



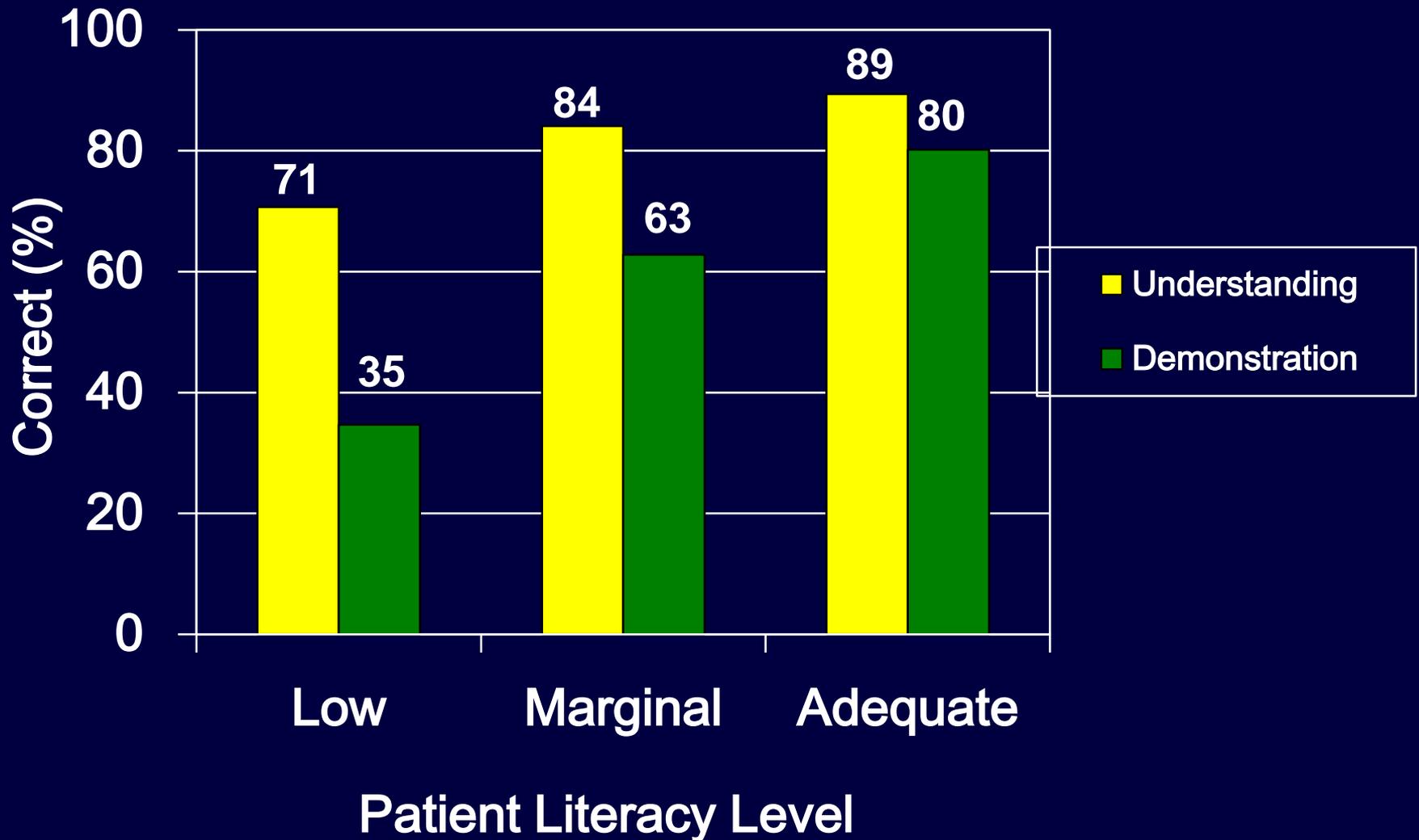
- 46% did not understand instructions  $\geq$  1 labels
- 38% with adequate literacy missed at least 1 label



# “Show Me How Many Pills You Would Take in 1 Day”



# Rates of Correct Understanding vs. Demonstration “Take Two Tablets by Mouth Twice Daily”



# Low Literacy Related to Worse Control of Chronic Illness

- Diabetes
  - Worse glycemic control
  - More long-term sequelae
- HIV
  - Higher viral load
- Depression
  - More severe disease
- Hospitalization
  - Consequence of several diseases



DeWalt, et al. JGIM 2004;19:1228-1239

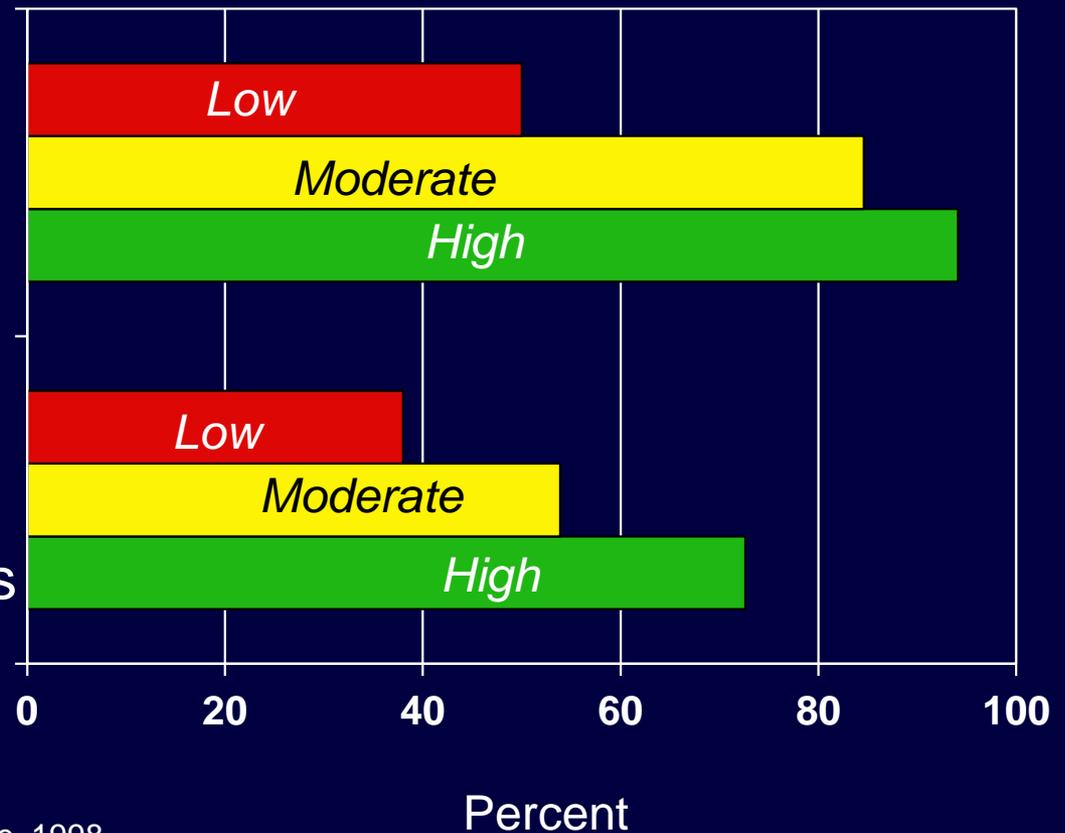
# Low Literate Diabetic Patients Less Likely to Know Correct Management\*

## ***Need to Know:***

symptoms of low blood sugar (hypoglycemia)

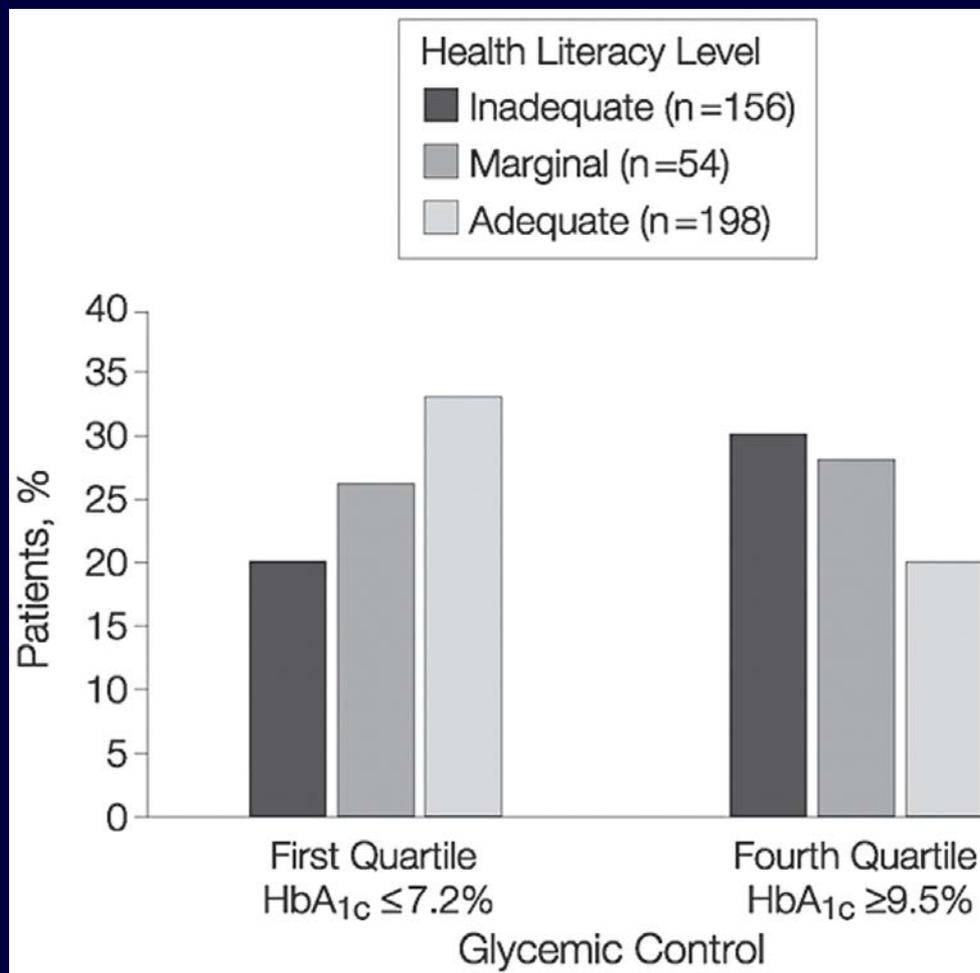
## ***Need to Do:***

correct action for hypoglycemic symptoms



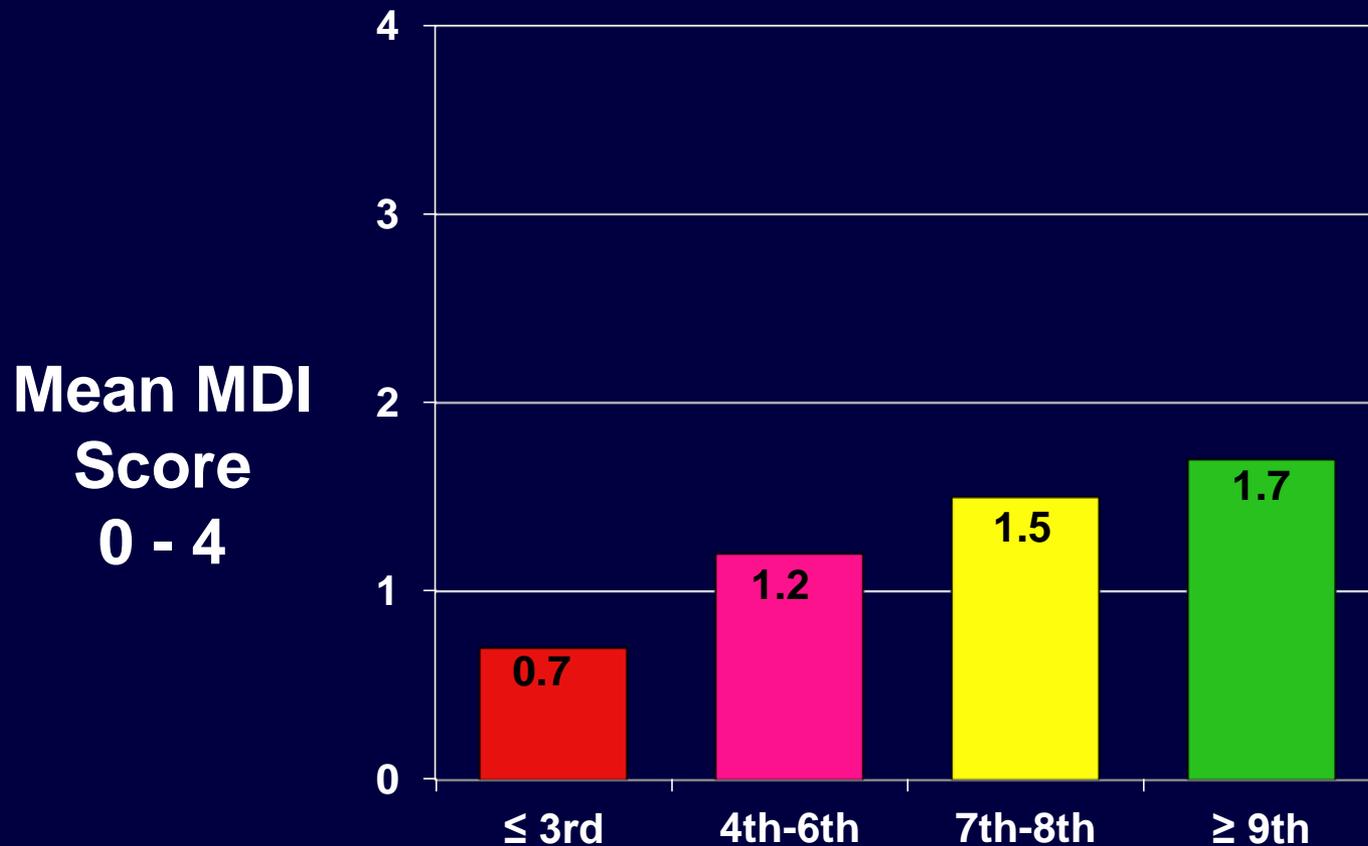
\*Williams et al., Archive of Internal Medicine, 1998

# Literacy Level and Glycemic Control



Schillinger, D. et al. JAMA 2002;288:475-482.

# Asthma Patients with Low Literacy have Poorer Metered Dose Inhaler (MDI) Skills



Williams et al. *Chest* 1998, 114(4):1008-1015.

# Adult Hospitalization

- People with low literacy have 30-70% increased risk of hospitalization
- RR = 1.29 (1.07-1.55) Medicare Managed Care
- RR = 1.69 (1.13-2.53) Urban Public Hospital

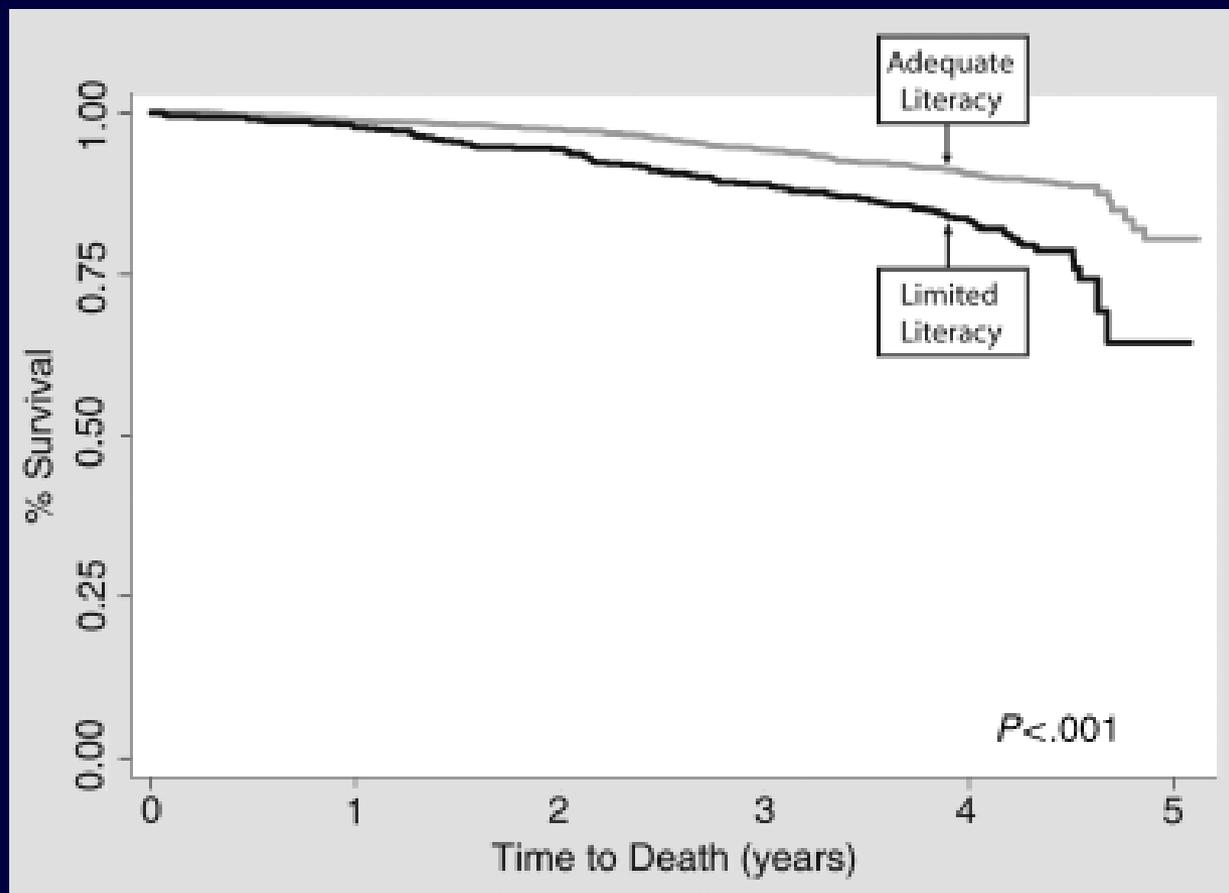
\*Adjusted for age, gender, socioeconomic status, health status, and regular source of care.

Baker et al. AJP. 2002. 92:1278.

Baker et al. JGIM. 1998. 13:791.



# Literacy and Mortality



Health, Aging, and Body Composition Study

Sudore et al. JGIM 2006; 21: 806-812



# What Can We Do?

# Interventions to Improve Health Outcomes for Patients with Low Literacy

- Raise awareness among providers
- Develop easier to read materials
- Improve communication skills
- Practice-redesign
- Literacy training / adult education



# Can Patients Comprehend Rx Drug Warning Labels?



Davis et al. JGIM 2006; 21: 847-851

# Simple Familiar Wording Understood by Most Patients



84%

(1<sup>st</sup> grade.)

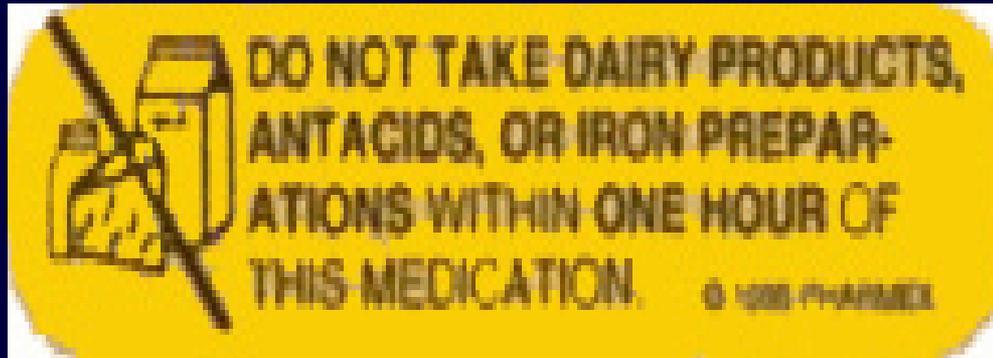
# More Complex Message Limited Comprehension



59%

(10<sup>th</sup>-12<sup>th</sup> grade.)

# Unfamiliar Multi-step Instructions Rarely Understood

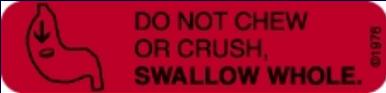


8%

(12<sup>th</sup>-13<sup>th</sup> grade)

# Comprehension Increased with Patient Literacy Level

\* p<.0001, † p<.05

	<u>&lt;6</u>	<u>7-8</u>	<u>&gt;9</u>
	79%	86%	88% †
	35%	66%	78% *
	8%	64%	82% *
	0%	6%	15% *
			

**In multivariate analysis only literacy and age predicted comprehension.**

Patients with low literacy (< 6th gd.) 3x more likely to incorrectly interpret warning labels.

Davis et al. JGIM 2006; 21:847–851.

# What does this picture mean?



- “Someone swallowed a nickel”
- “Indigestion”
- “Bladder”
- “Looks like a ghost- Casper”

# Raising Awareness

- Relatively easy, low cost intervention with excellent reach
- Low efficacy when used alone, particularly for lecture format



# Example: Screening for Literacy Randomized Controlled Trial

- Physicians randomized to receive feedback on patients' literacy levels
- 441 patients screened
- 229 scored inadequate or marginal on S-TOFHLA and were included in the trial

Seligman et al. JGIM 19(S1): 208; 2004.

# Results

- Physicians more likely to use extra teaching strategies (good!)
- Physicians less satisfied with visit
- 94% of patients felt literacy screening was useful
- No improvement in A1C

Seligman et al. JGIM 19(S1): 208; 2004.



# Educational Materials

- Good health information is often hard to come by
- Most health information written at too high of a reading level
- Few health care systems have comprehensively integrated educational materials in their overall care plans



# Use Patient-Friendly Educational Materials

- Simple wording, short sentences
  - 4<sup>th</sup>-6<sup>th</sup> grade level
- Picture based
- Focus only on key points
- Emphasize patient concerns
  - What the patient may experience
  - What the patient should do
- Minimize information about disease statistics, anatomy, and physiology
- Be sensitive to cultural preferences



# Information Recommended by Guidelines

- General topics
- Explanation of heart failure
- Expected symptoms vs symptoms of worsening heart failure
- Psychological responses
- Self-monitoring with daily weights
- Action plan in case of increased symptoms
- Prognosis
- Advanced directives
- Dietary recommendations
- Sodium restriction
- Fluid restriction
- Alcohol restriction
- Compliance strategies
- Activity and exercise
- Work and leisure activities
- Exercise program
- Sexual activity
- Compliance strategies
- Medications
- Nature of each drug and dosing and side effects
- Coping with a complicated regimen
- Compliance strategies
- Cost issues

*Grady et al. Circulation. 2000;102(19):2443-2456.*



# Patient Education Materials

## Example: Heart Failure

# Development of Educational Materials

- Distilled to essential information
- Collaborated with medical illustrator
- Focus group feedback
- Cognitive interviews
- Revised materials



# MANAGING YOUR HEALTH WITH HEART FAILURE

1

2

3



UNC School of Medicine and Department of Pharmacy (Working Group on Health Risk Communication) 919-843-6480

<http://www.shareddecisionmaking.org>



NC Program on Health Literacy



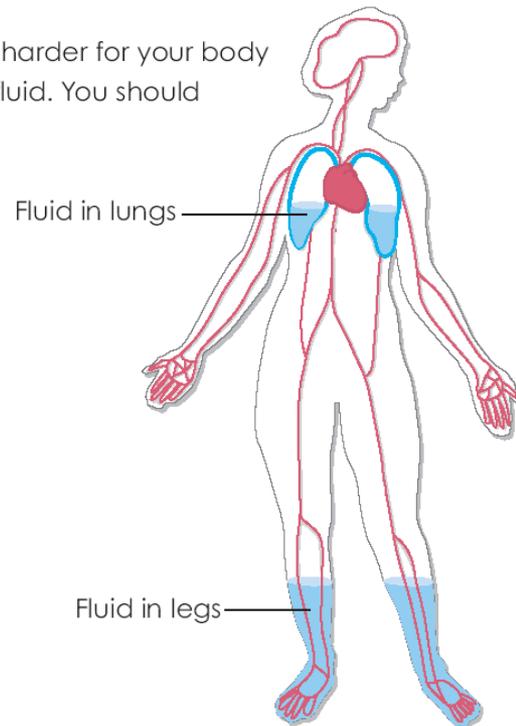
# Congestive Heart Failure

With congestive heart failure, the heart cannot pump the blood well. As a result, blood doesn't flow well.

Fluid leaks out of your blood vessels and backs up in the lungs and the legs.



Salt makes it harder for your body to get rid of fluid. You should avoid salt.



# How Bad Is Your Congestive Heart Failure?

You can tell how well your heart is doing by how you feel and what you can do.

## SWELLING

Good – No Swelling



OK – Swelling in Ankle or Shin



Bad – Swelling in Knee Area



Call the UNC Clinic / 919-843-6480 ☎

## WALKING

Good – You can walk easily with no shortness of breath



OK – Shortness of breath when walking fast



Bad – Short of breath at rest



Call the UNC Clinic / 919-843-6480 ☎

## SLEEPING

Good – Sleeping flat, no shortness of breath



OK – Needing 2 pillows or more to avoid shortness of breath



Bad – Have to sleep upright to avoid shortness of breath



Call the UNC Clinic / 919-843-6480 ☎<sup>3</sup>

# Living with Heart Failure Program

- Focus on self-management training
  - 1-hour individualized education session
  - Education booklet < 6th grade level
  - Scheduled follow-up phone calls
- Digital bathroom scale provided
- Easy access to care team (1-800 number)
- Help with barriers to care
- No efforts to adjust/change medication

# Additional Program Elements

- Scheduled phone calls
- Reinforce teaching
- Motivate patients
- Address transportation barriers
- Help patients enroll in pharmacy assistance program

# Organized Self-care Education Improves Health Outcomes

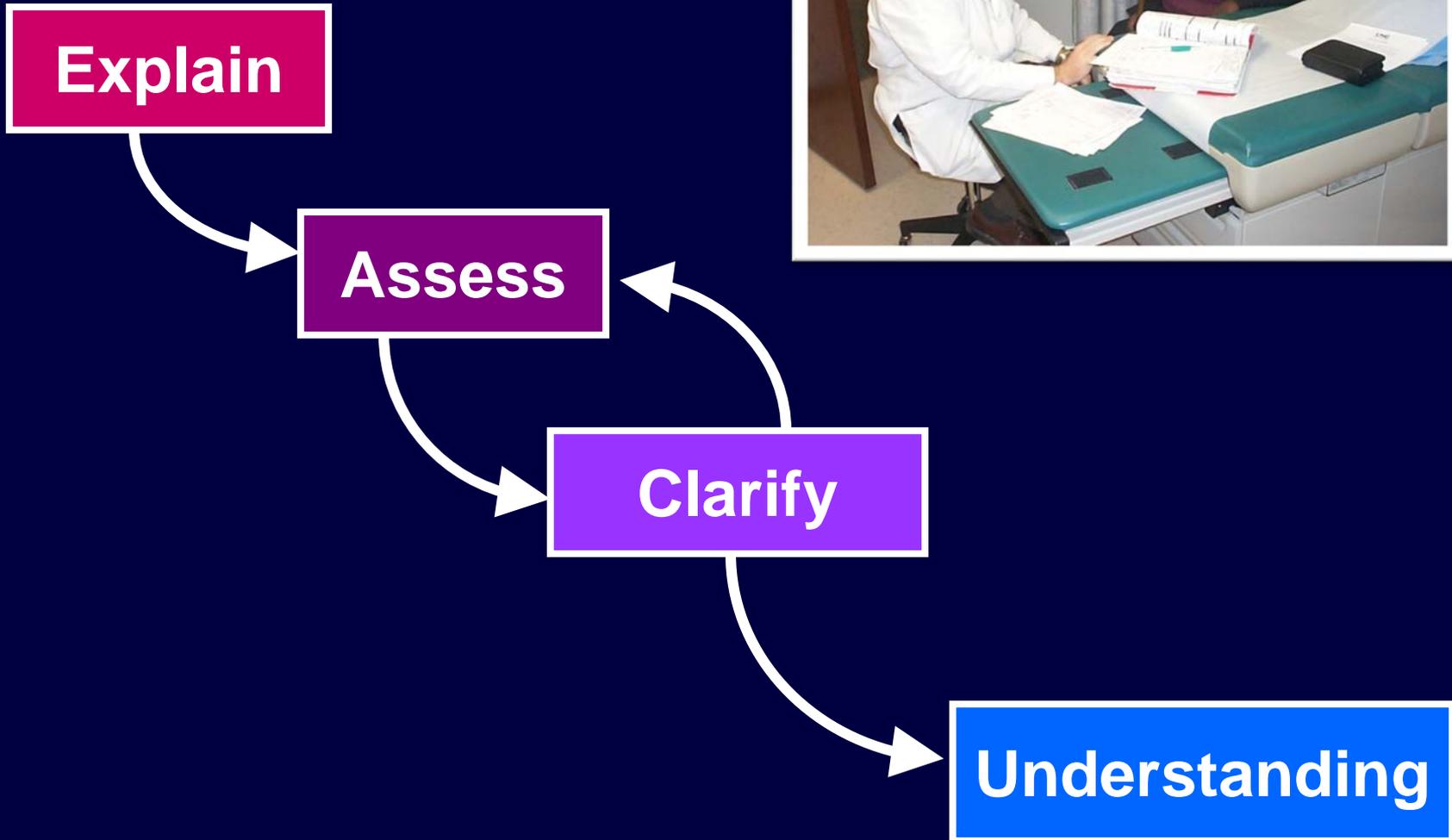
- Trial of intensive educational program vs. generic HF brochure
- Intervention reduced incidence of hospitalization or death: IRR 0.56 [0.32, 0.95]
- Low literacy patients seemed to benefit more: adjusted IRR 0.38 [0.16, 0.88]

# Improved Communication: “Teach-back”

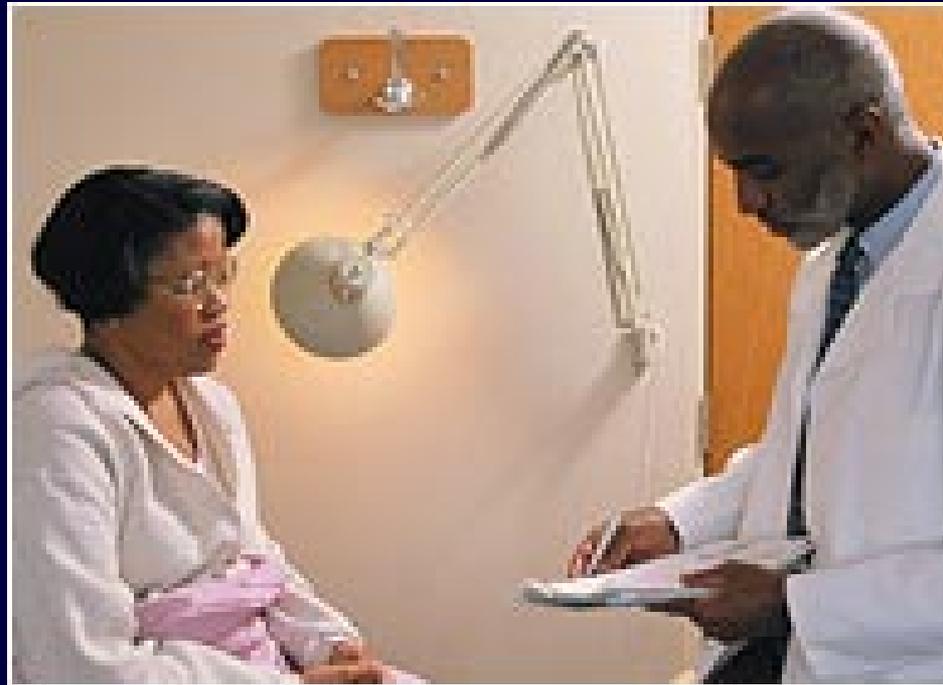
- Ensuring agreement and understanding about the care plan is essential to achieving adherence
- “We don’t always do a great job of explaining our care plan. Can you tell me in your words how you understand the plan?”
- Some evidence that use of “teach-back” is associated with better diabetes control



# Teach-back



# Practice Re-design Example: Diabetes Care



# Diabetes Disease Management

- Tracking registry
- Patient education
- Care coordination
- Phone follow-up
- Use of treatment and monitoring algorithms
- Address barriers of insurance, transportation, and communication



# Educational Strategies

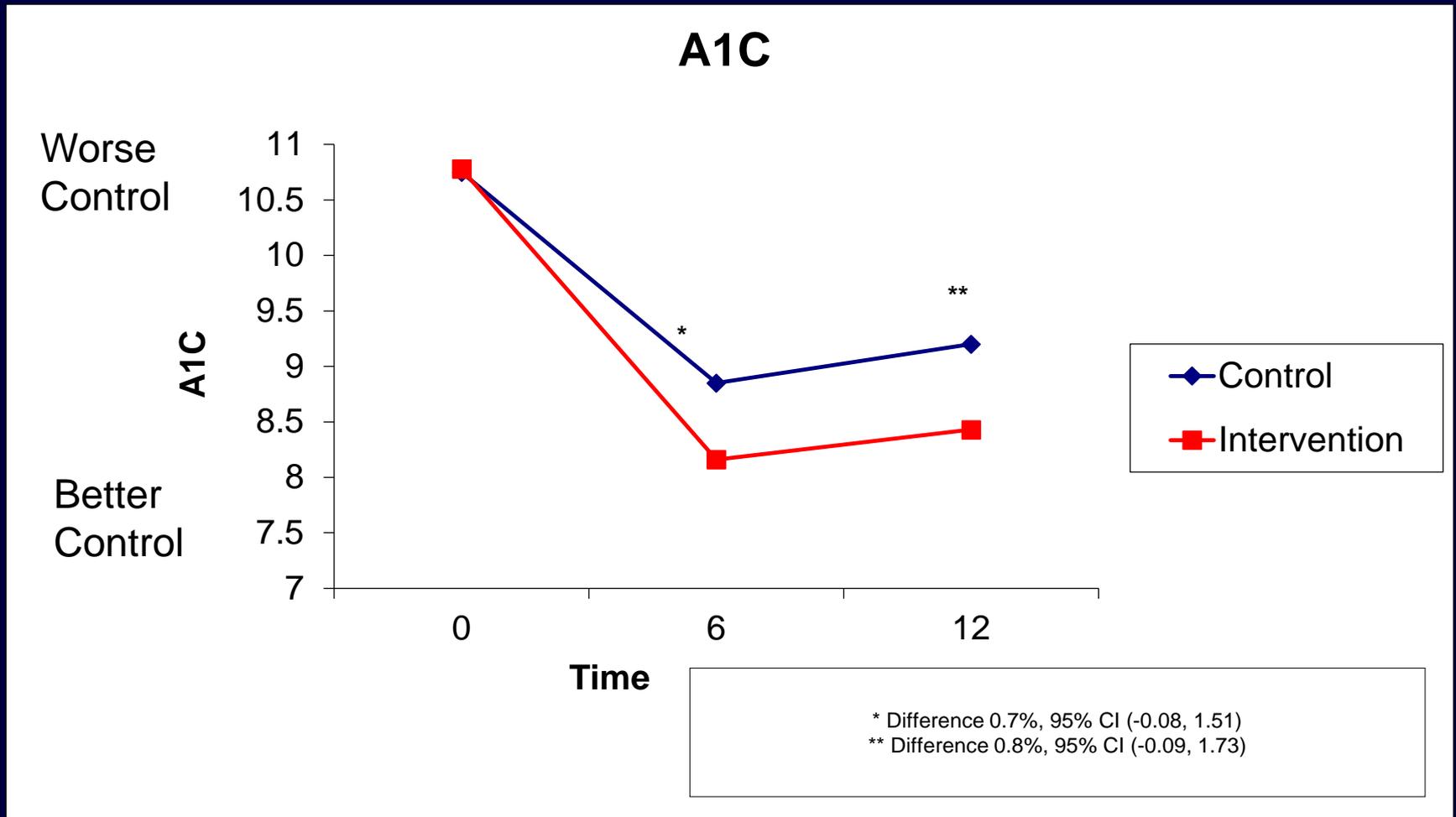
- Patient centered learning
- Therapeutic alliance
- Teach-back method
- Repetition/reinforcement
- Survival skills

# Care Coordination

- Call patient at least once a month
- Review self-care skills
- Help to navigate health care system

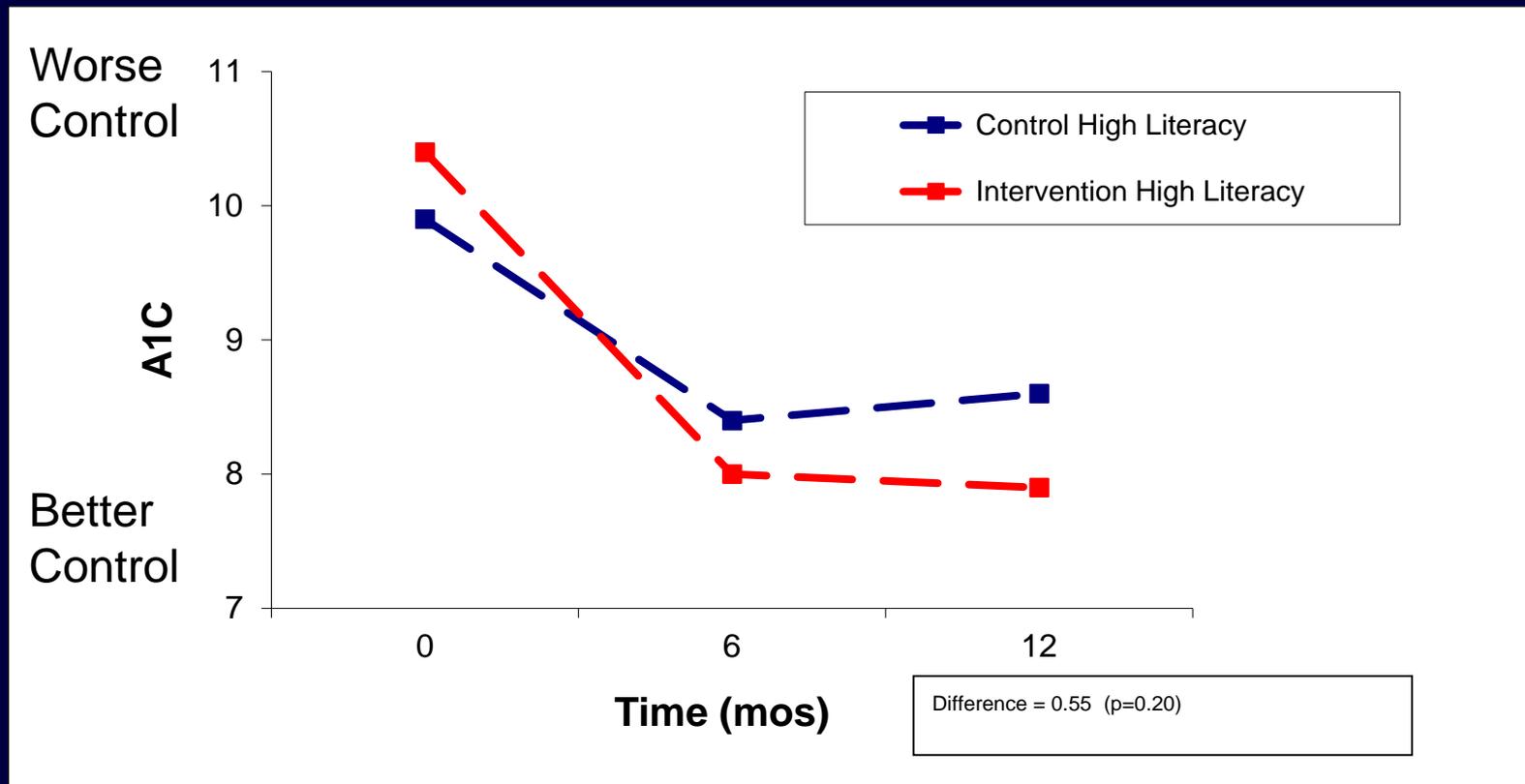


# Improvement in HbA1c



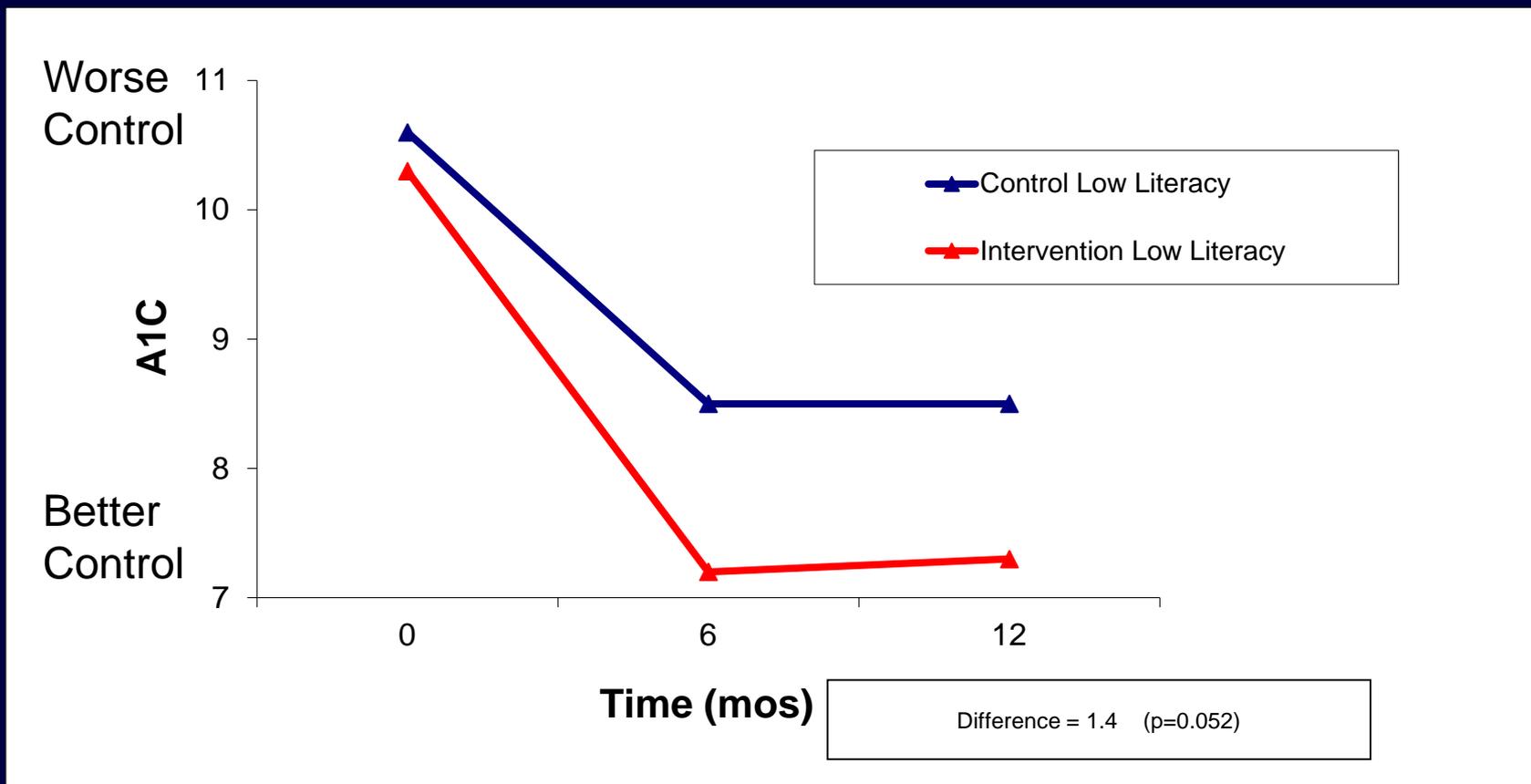
Rothman et al. Am J Med 2005; 118:276-284.

# Diabetes Control: Results for Patients with Literacy Above 6th Grade Level



Rothman et al. *JAMA* 2004, **292**(14):1711-1716.

# Diabetes Control: Results for Patients with Literacy at or Below 6<sup>th</sup> Grade Level



Rothman et al. *JAMA* 2004, **292**(14):1711-1716.

# Literacy Training

- Improving patients' reading ability helps address underlying problem
- Resource-intensive: requires significant time and effort for students and teachers
- Goal: one year of adult education can produce one additional grade level in reading skill
- Small improvements may have big effects on patient health outcomes and well-being



# Literacy Training Example: Montana Program

- Randomized trial of 70 patients with depression
- Allocated to standard depression treatment alone vs. standard treatment + literacy education (mean of 18 hours)
- Intervention patients had greater improvement in depression scores

Weiss JGIM 2006; 21:823-8

# Summary

- Low literacy is common and is associated with adverse health outcomes
- Interventions to mitigate the impact of literacy on health have not been well-studied
- Some evidence suggests that practice system changes and perhaps adult education can improve outcomes

# The End

Last updated 12.09.08

Individuals are welcome to use the slides in this presentation. Please credit authors and the presentation creators. Thank you.