

Past Is Prologue: Future Directions in Health Literacy Research

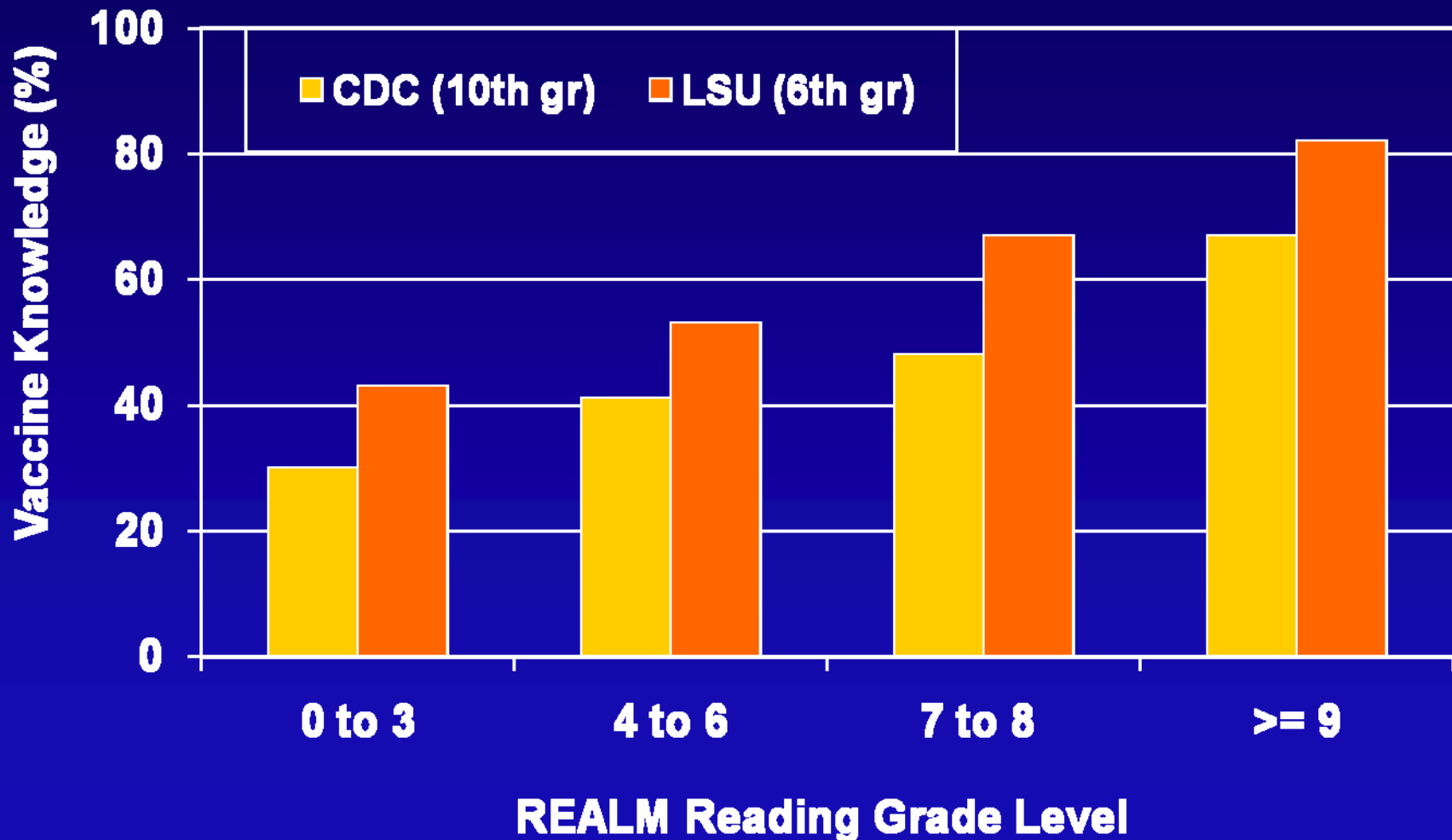
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Northwestern University
Chicago, Illinois

Health Literacy Annual Research Conference
October 19, 2008
Washington, D.C.



Beyond Plain Language

Simplified Polio Vaccine Brochure Improves Comprehension



TC Davis. Pediatrics '96

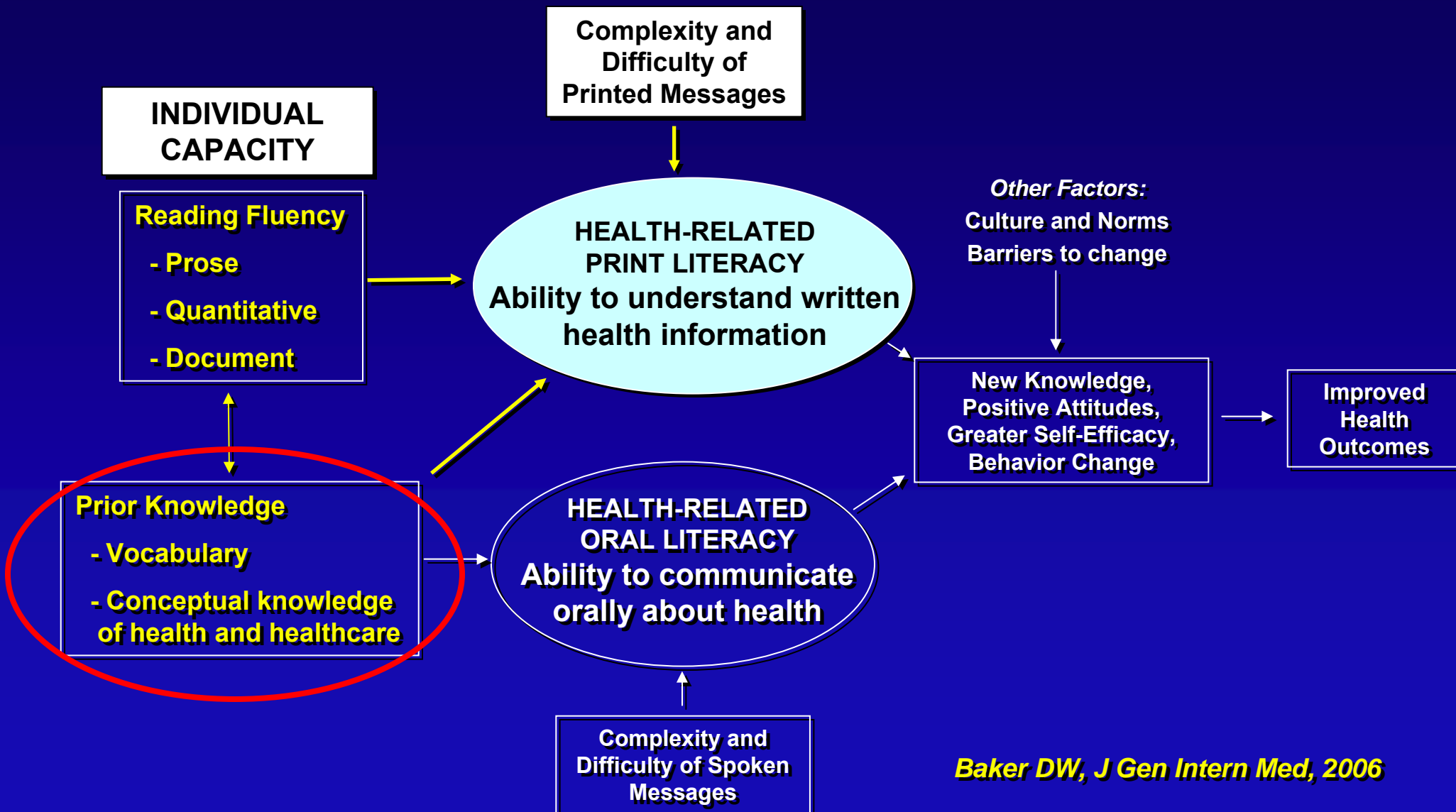
Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
- When are print materials not enough?
- What are the limits of multimedia?
- What is the role of patient narratives?
- Can we teach patients less and activate them more?

Beyond Plain Language

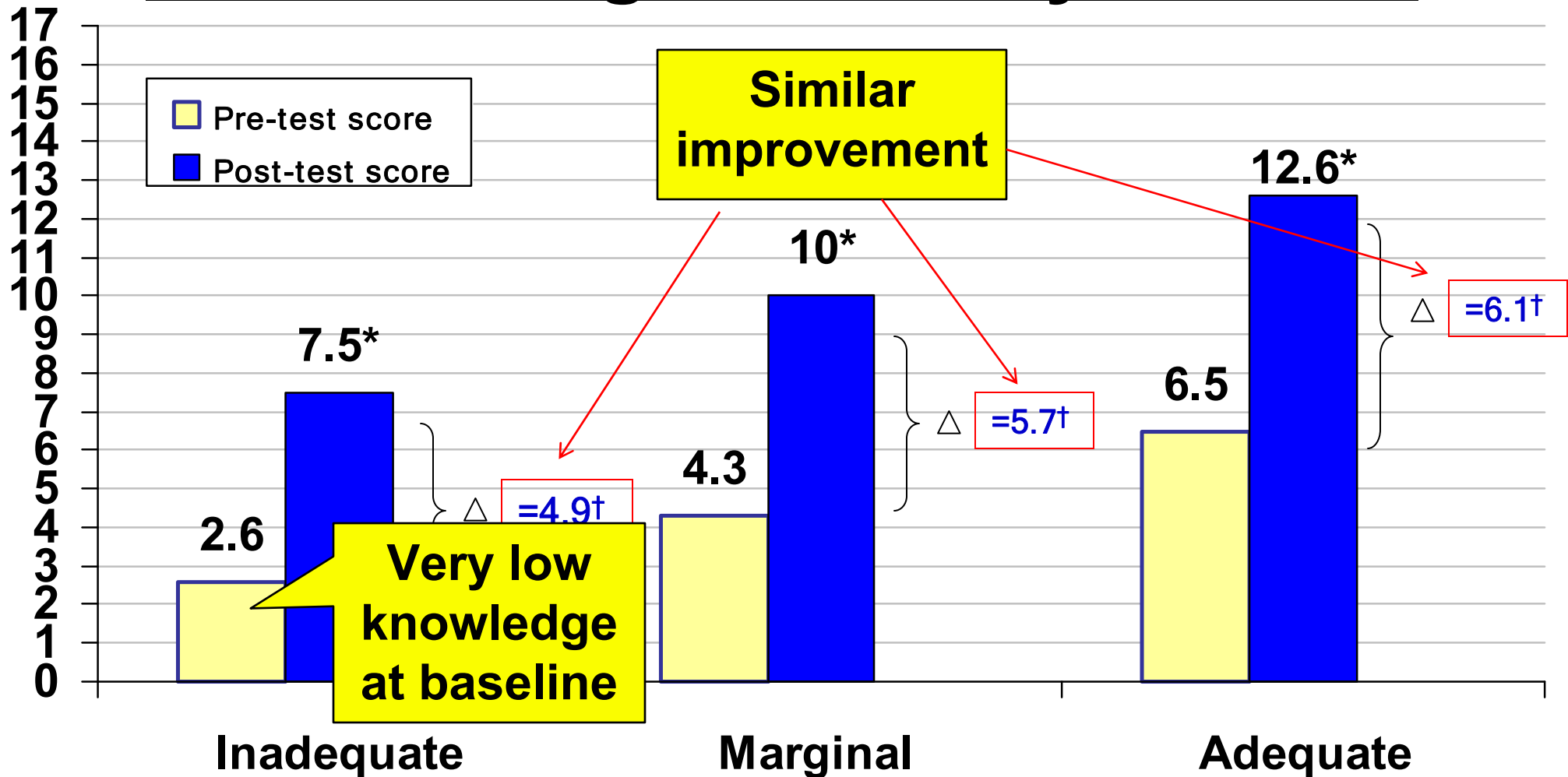
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Conceptual Model of Health Literacy

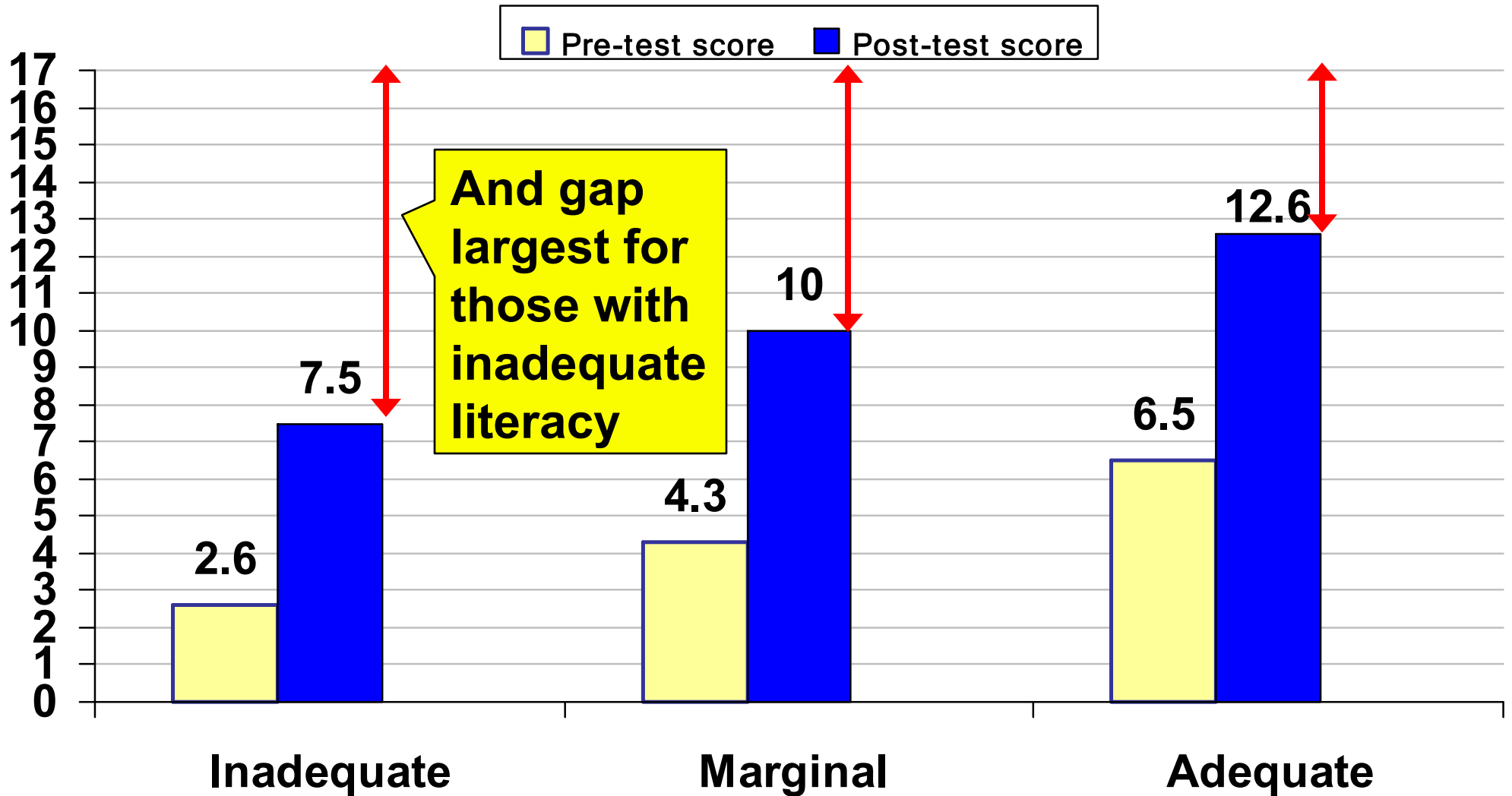


Baker DW, J Gen Intern Med, 2006

Diabetes Knowledge Gained According to Literacy Level



But Large Gap Remains



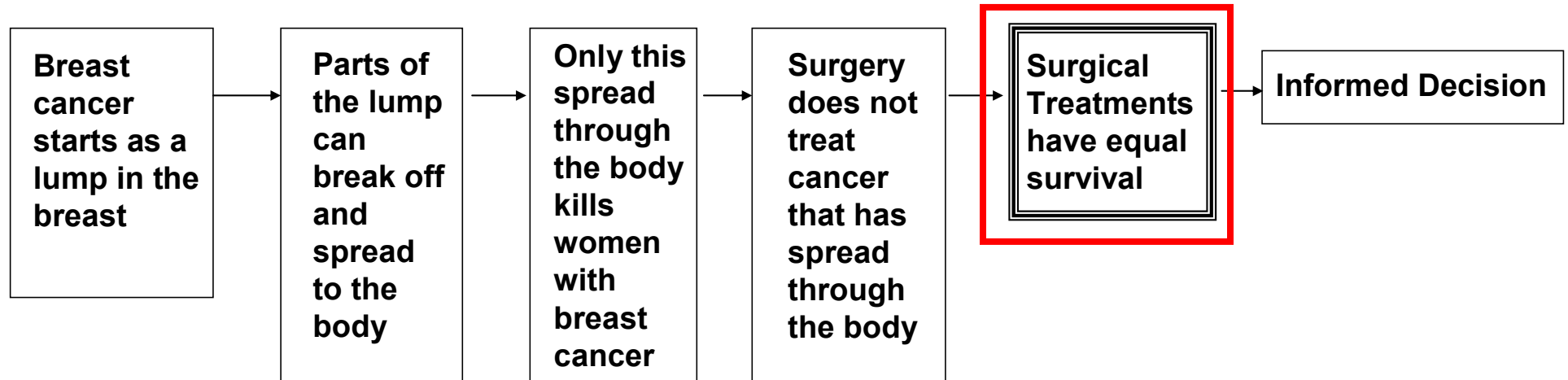
Structured Learning

- Low literate often lack prerequisite knowledge required for higher level learning
- To overcome this, we need to:
 - Define learning objectives
 - Analyze learning tasks and define challenges, including background knowledge needed to truly comprehend
 - Design instructional sequence
 - Verbal information, rules, concepts
 - Problem solving

Principles of Instructional Design. Gagné RM

What Do Patients Need to Know Before They Are Ready for Key Messages?

Your chances of long-term survival with early breast cancer are the same with lumpectomy and XRT and mastectomy



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Quantitative Skills (Numeracy):

Is your blood sugar normal today?

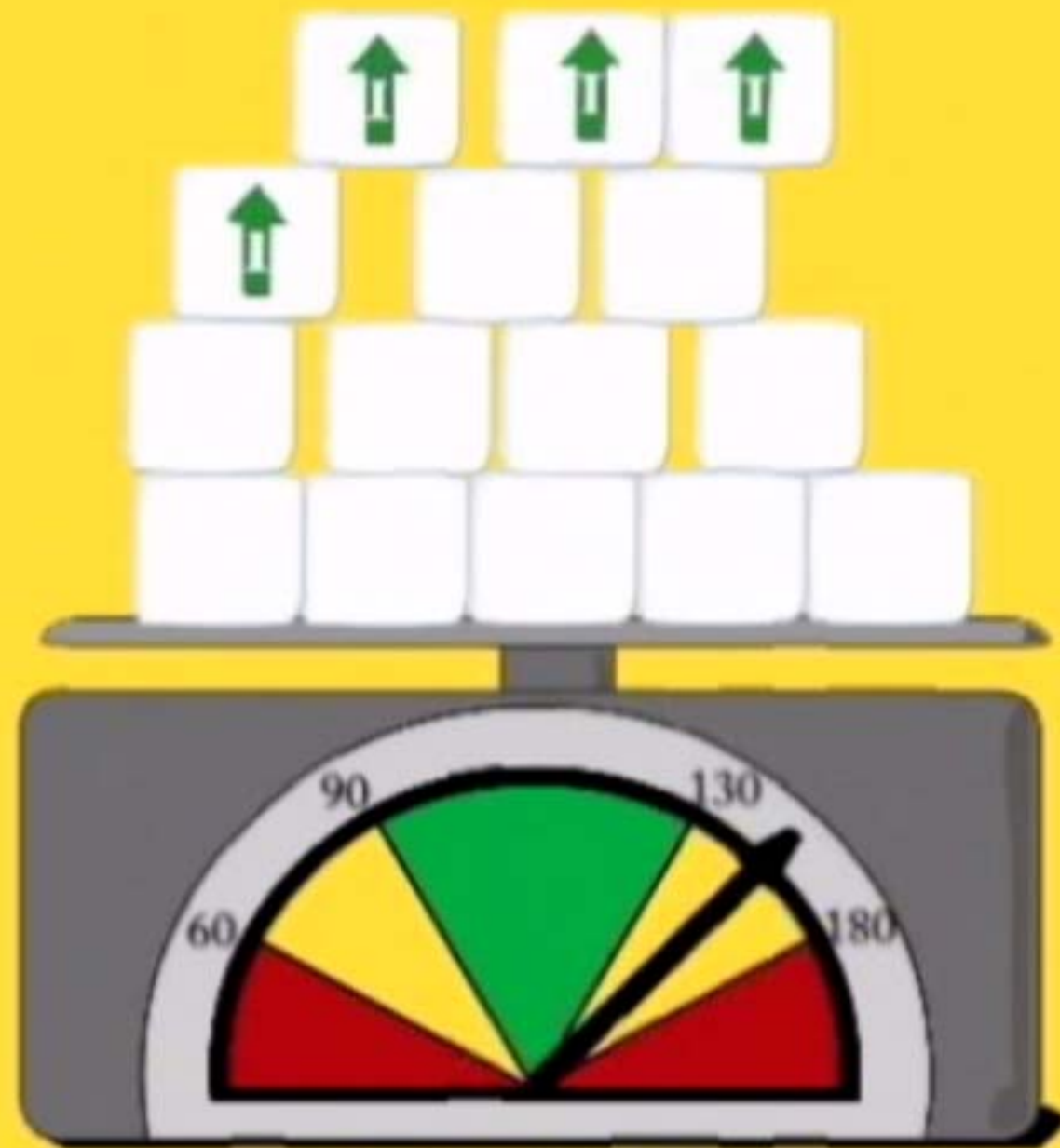
Normal blood sugar is 60 - 150.

Your blood sugar today is 160.

37% Unable to Answer Correctly

Multimedia for Communicating Complex Ideas

- Everyone has sugar in their blood
- It comes from the food you eat: even foods that don't taste sweet have sugar
- Your body needs sugar to function
- But too much sugar is bad: that's diabetes
- Your goal is to have just the right amount of sugar: not too much, not too little



TOO HIGH

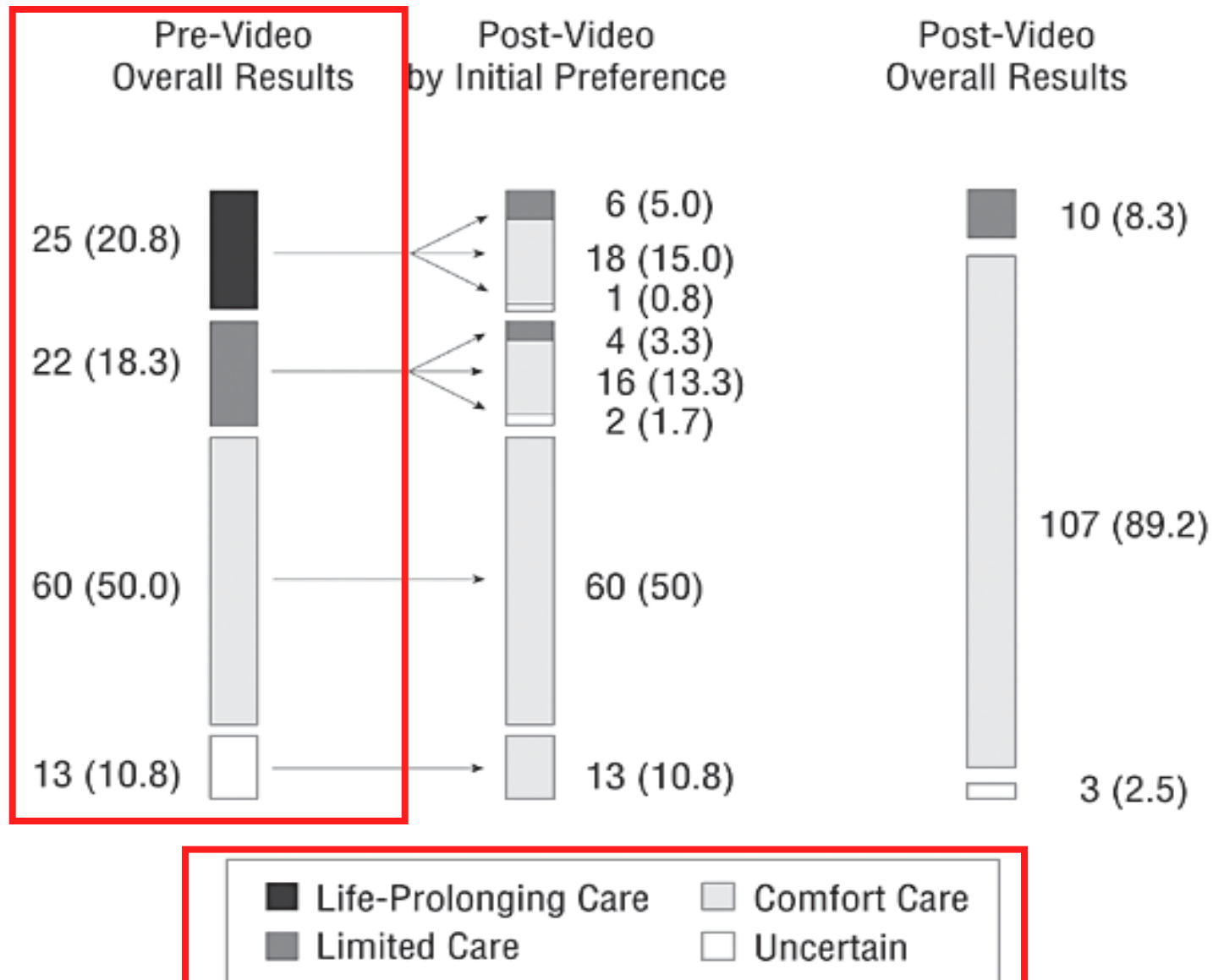
Multimedia for Communicating Ideas that Words Alone Cannot Adequately Convey:

Deciding Preferences for End of Life Care

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

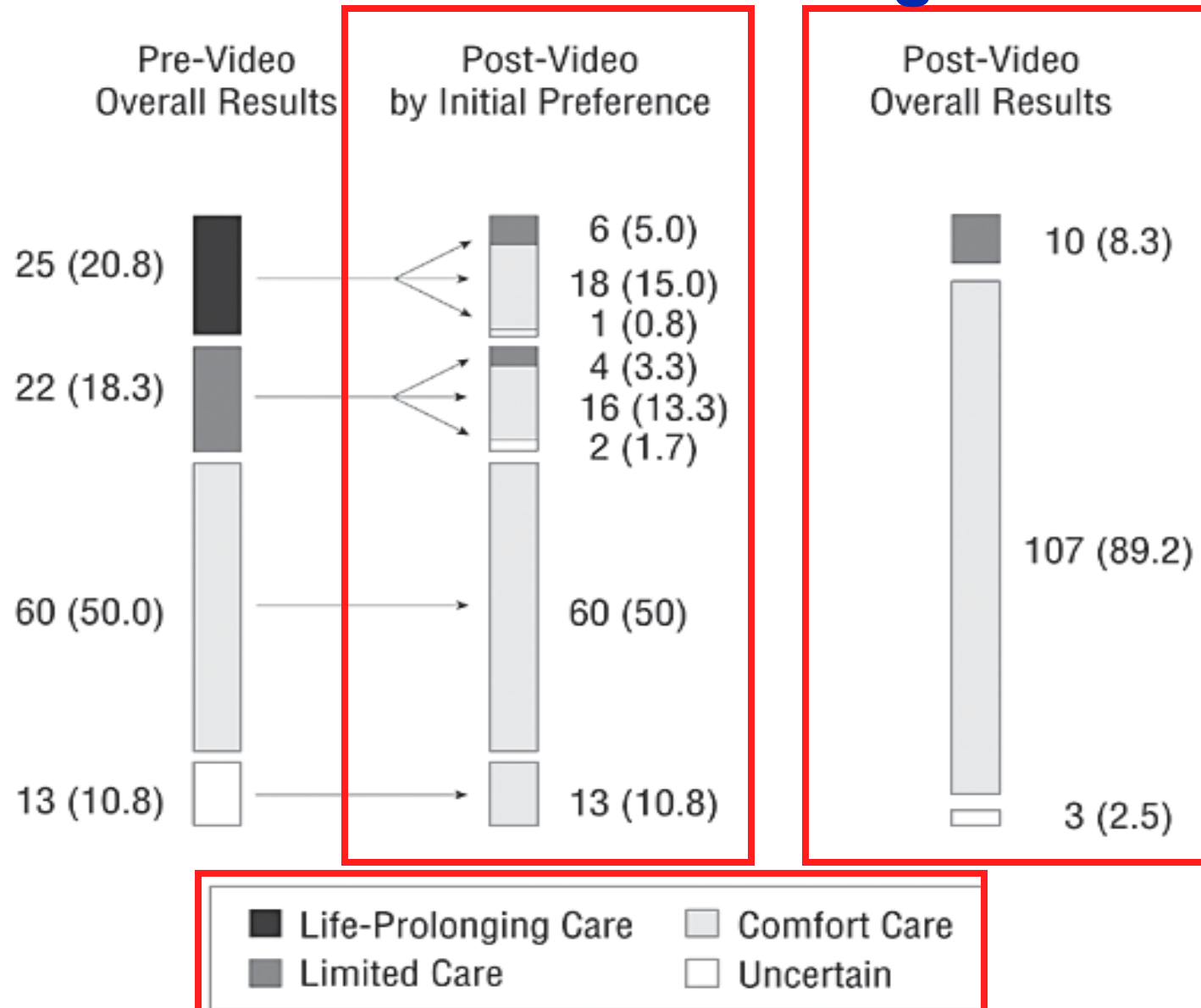
Volandes, A. E. et al. Arch Intern Med 2007;167:828-833.

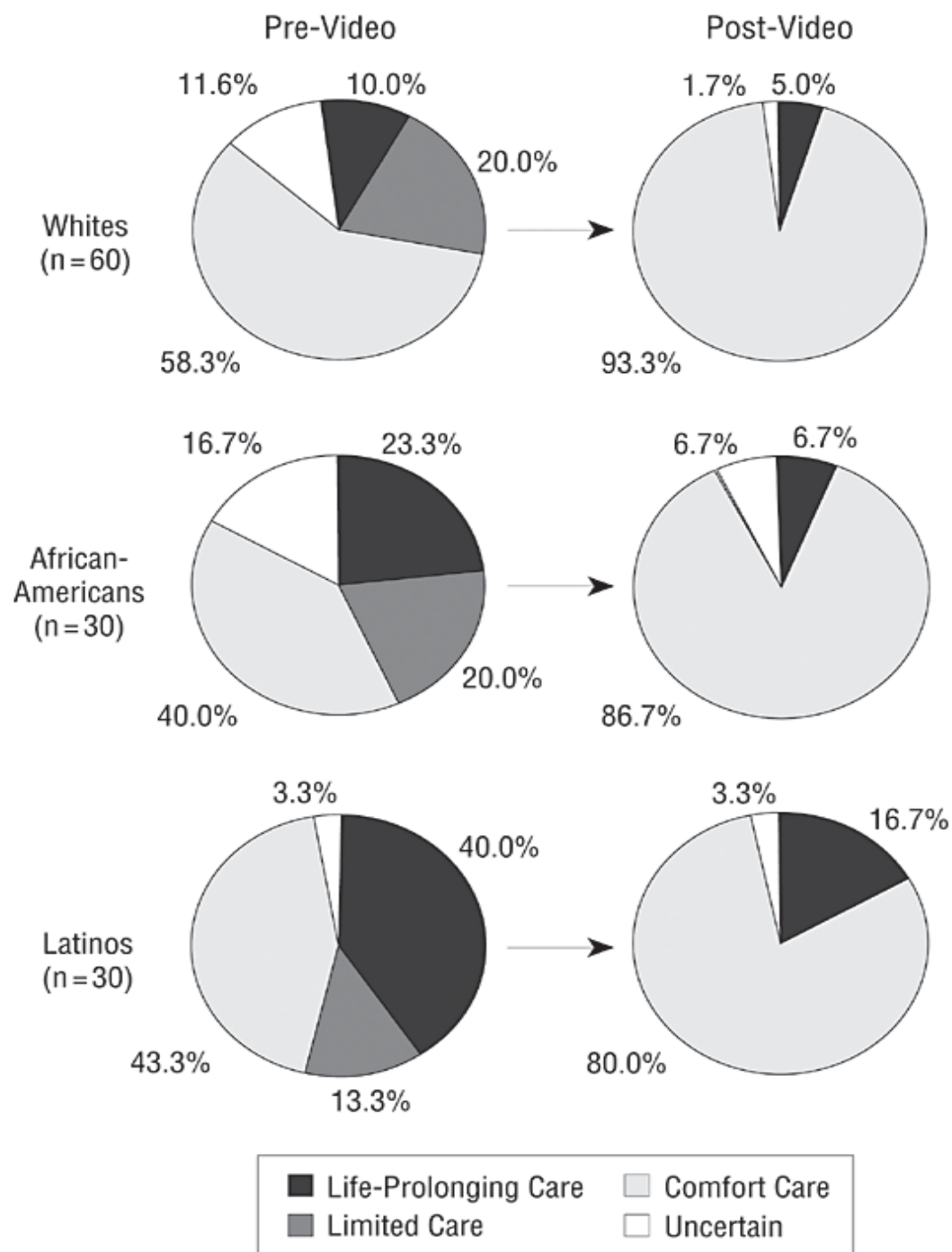
Patient Preferences for Level of Medical Care Before and After Watching Video





Patient Preferences for Level of Medical Care Before and After Watching Video



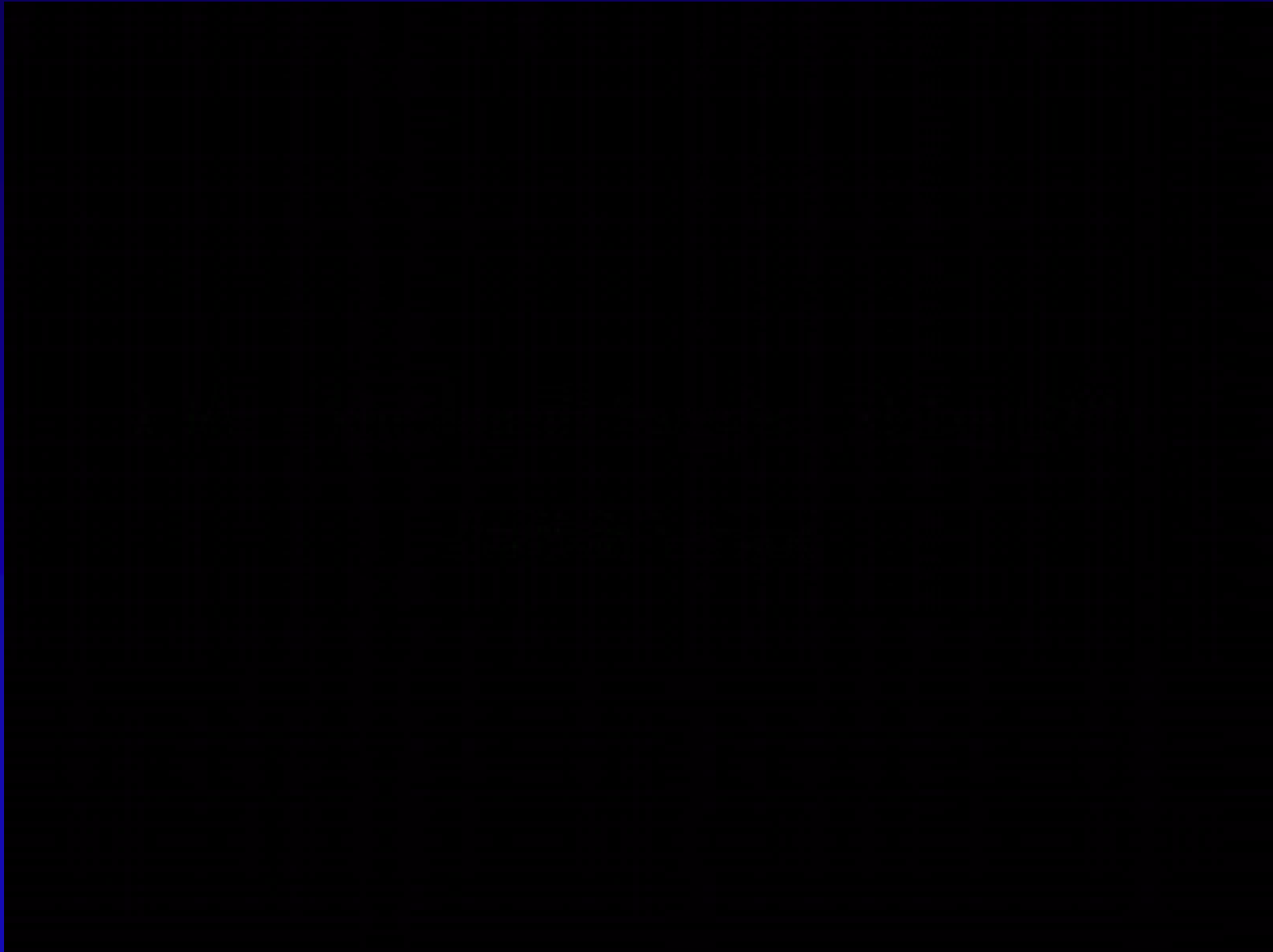


**Differences in
Preferences for
Whites, Blacks,
and Latinos
Diminished
Greatly after
Watching Video**

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Diabetes Foot Care Module



The Limits of Multimedia

- General concepts or analogies communicated well
- May powerfully change attitudes
- Information goes by very quickly
 - Particularly problematic if low knowledge base
 - Elderly have slower information processing speed

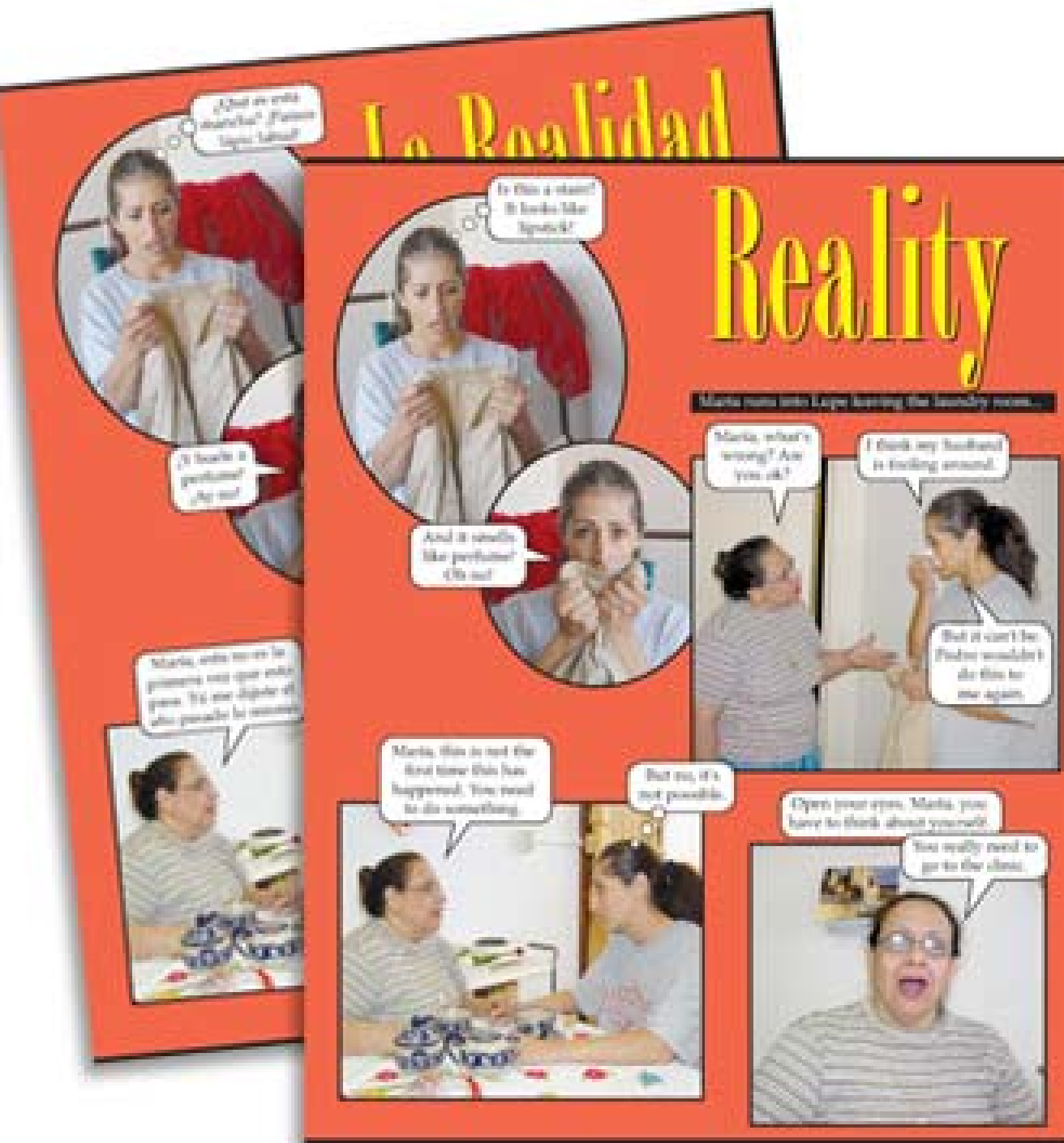
Overcoming the Fast Pace of Multimedia Programs

- “Virtual page turns”
 - Give short segment and stop
 - Viewer can repeat or go forward
 - Medline Plus uses this model
- Combine with print materials
 - “Reverse-engineered” print materials that follow as “companion guide”
- No studies to my knowledge about this

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Alternative to the Didactic Model of Behavior Change: A Social Cognitive Approach

Pros and Cons of Patient Narratives Are Unclear

- Advantages
 - Role modeling, social learning
 - May powerfully influence attitudes
- Disadvantages
 - May not be as successful for education
 - Information goes by quickly
 - Distractors, high “cognitive load”
- Optimal placement of narratives unclear

Use Narratives Carefully for Decision Aids

- Systematic review of the effect of narrative information on decision-making
- 17 studies: 41% 1st person, 59% 3rd person
- In 5 of 17 studies, narratives affected decision making, especially if 1st person
- Authors called for caution when using narratives as part of interventions to aid medical decision-making

Winterbottom A, et al. Soc Sci Med 2008

Beyond Plain Language

- What can we do to increase the effectiveness of educational materials?
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Just Do It?

- **Traditional model**
 - Knowledge, Attitudes, Behavior
- **Action model**
 - Less information, more goal setting
 - Identify options for behavior change
 - Patient testimonials

Examples of goals set by participants.

I will walk around my block one time 3 days a week.

I will dance with my granddaughter everyday for 10–15 min.

I will bring a healthy snack to work every other day.

I will look into water aerobics classes, and try at least one.

I will eat less fast food by cooking 1 meal a day.

I will read the chapter on eating right.

I will limit the desserts I eat to 2 store-bought sweets a week.

I will take my Lantus™ after work, at least 4 times a week.

To cut back on my drinking to a maximum of 15 drinks [alcoholic beverages] per week.

I will walk or jump 2 times a week for 5 min at 1 p.m.

Talk to a social worker about how I can find a place to live.

Cut in half the amount of bread I eat at breakfast and lunch.

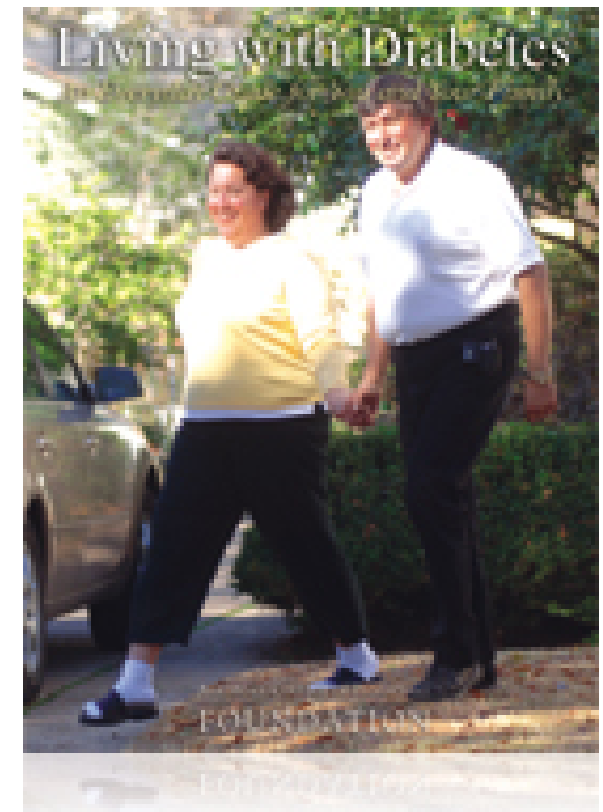
I will talk to my doctor about my depression.

I will ask for a new blood sugar monitor because my old one stopped working.

I will eat a half a candy bar instead of a whole candy bar for my after work snack.

Tuesday and Thursday nights I will eat only one serving of rice with dinner.

DeWalt DA, et al. Patient Educ Couns 2009



Recall and achievement of behavioral goals.

Follow-up	Remembered the action plan	Goal achieved and behavior sustained	Goal achieved, behavior not sustained	Goal not achieved, some behavior change	Other behavior change
2 weeks (n = 240)	95%	71%	2%	19%	44%
4 weeks (n = 232)	94%	66%	3%	22%	34%
12 weeks (n = 229)	88%	59%	3%	23%	45%
At all 3 follow-ups	79%	33%			

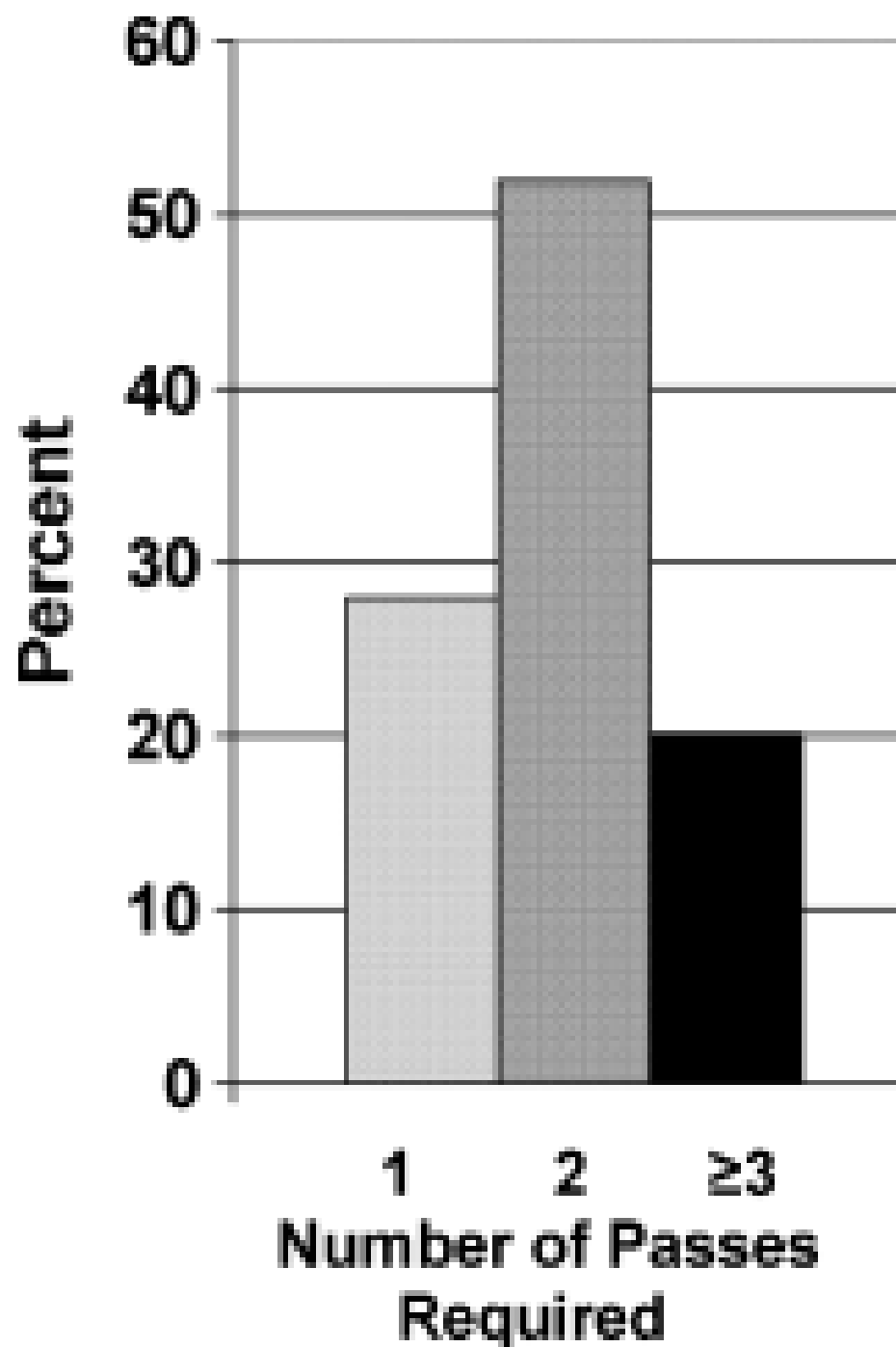
DeWalt DA, et al. Patient Educ Couns 2009

Beyond Teach Back

Learning Mastery Theory

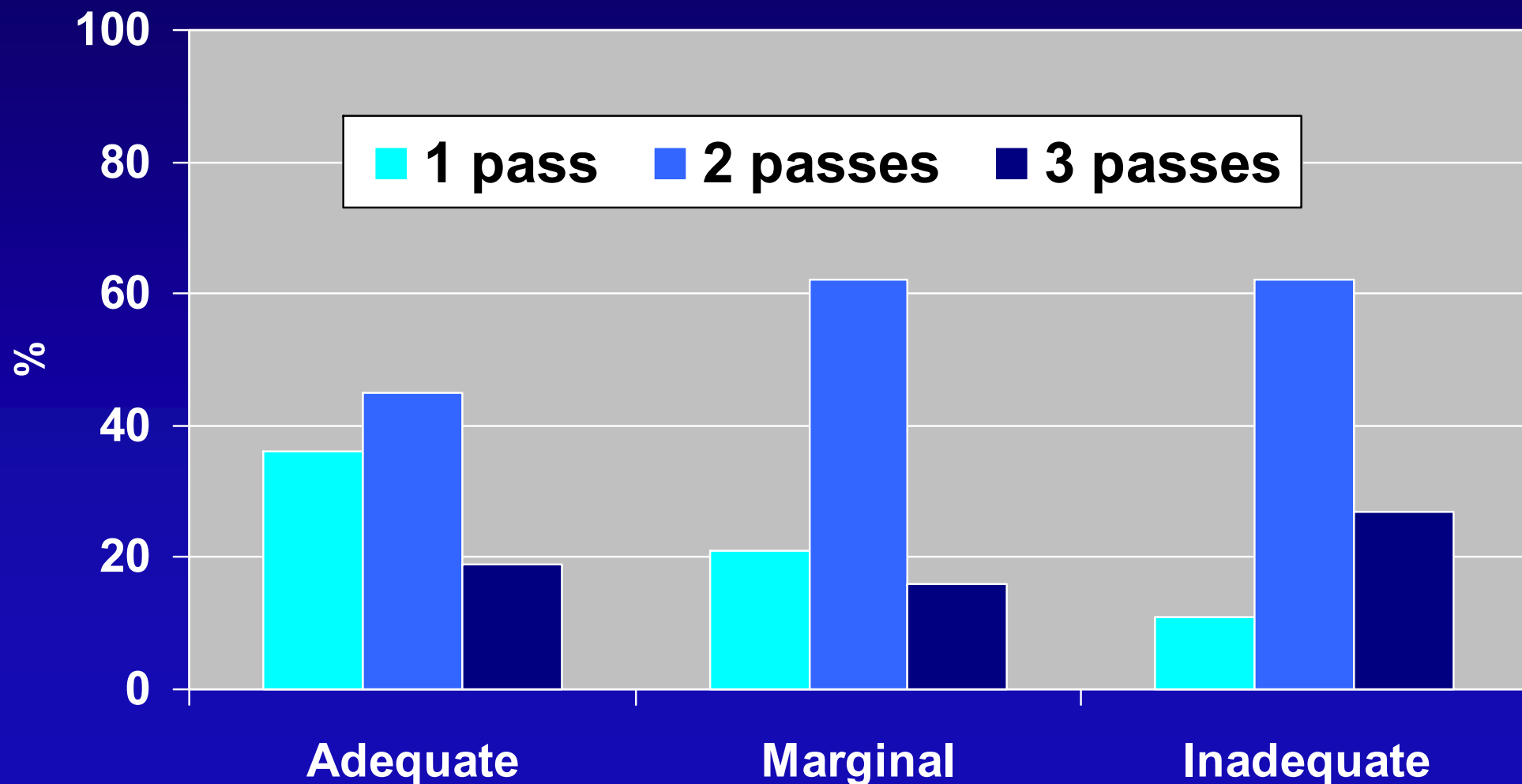
- Benjamin Bloom developed in 1950s
- Postulates that people differ in the *speed* at which they learn information (i.e., the number of repetitions required)
- Level of mastery is determined by the time devoted to teaching divided by the time required for learning
- Low literate will usually require more repetition of the material to master it

Most Patients Required Multiple Repetitions to Master Informed Consent

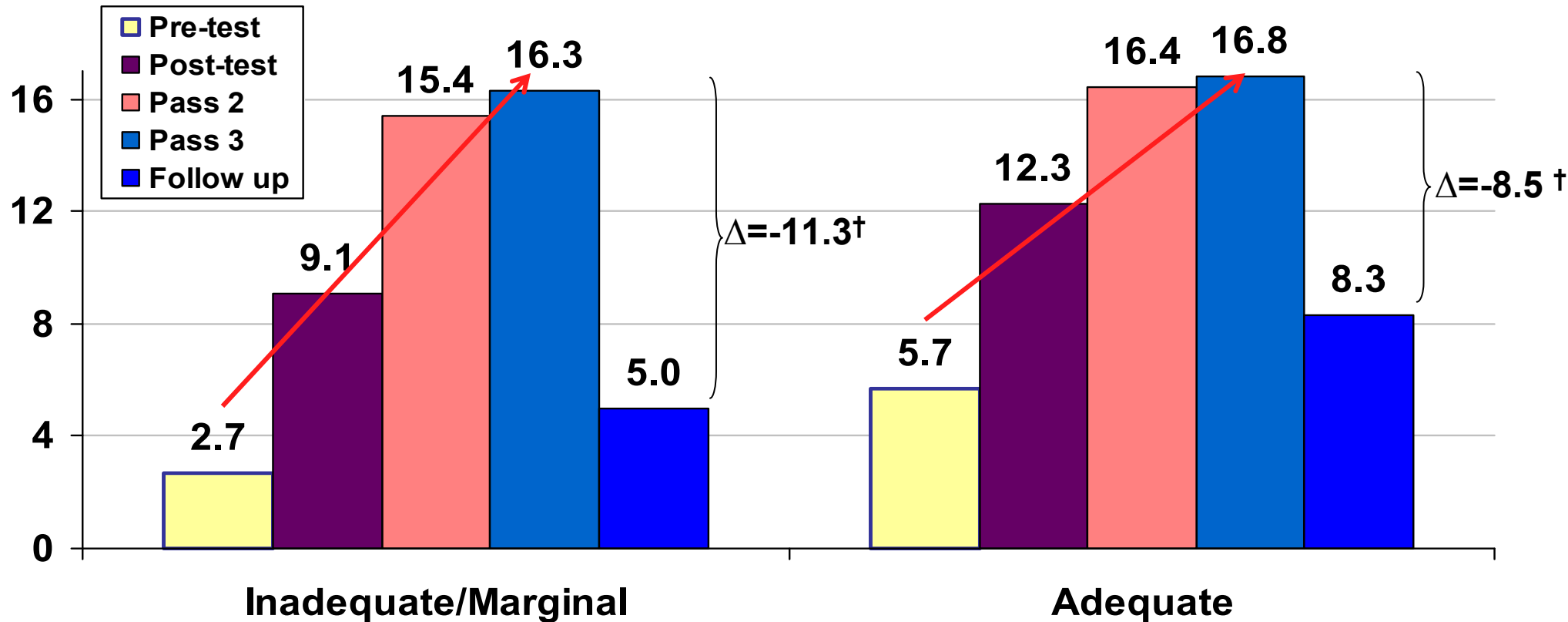


*Sudore RL, et al
JGIM '06*

Rate of Mastery Somewhat Higher for Patients with Higher Literacy, but Almost All Need Repetition



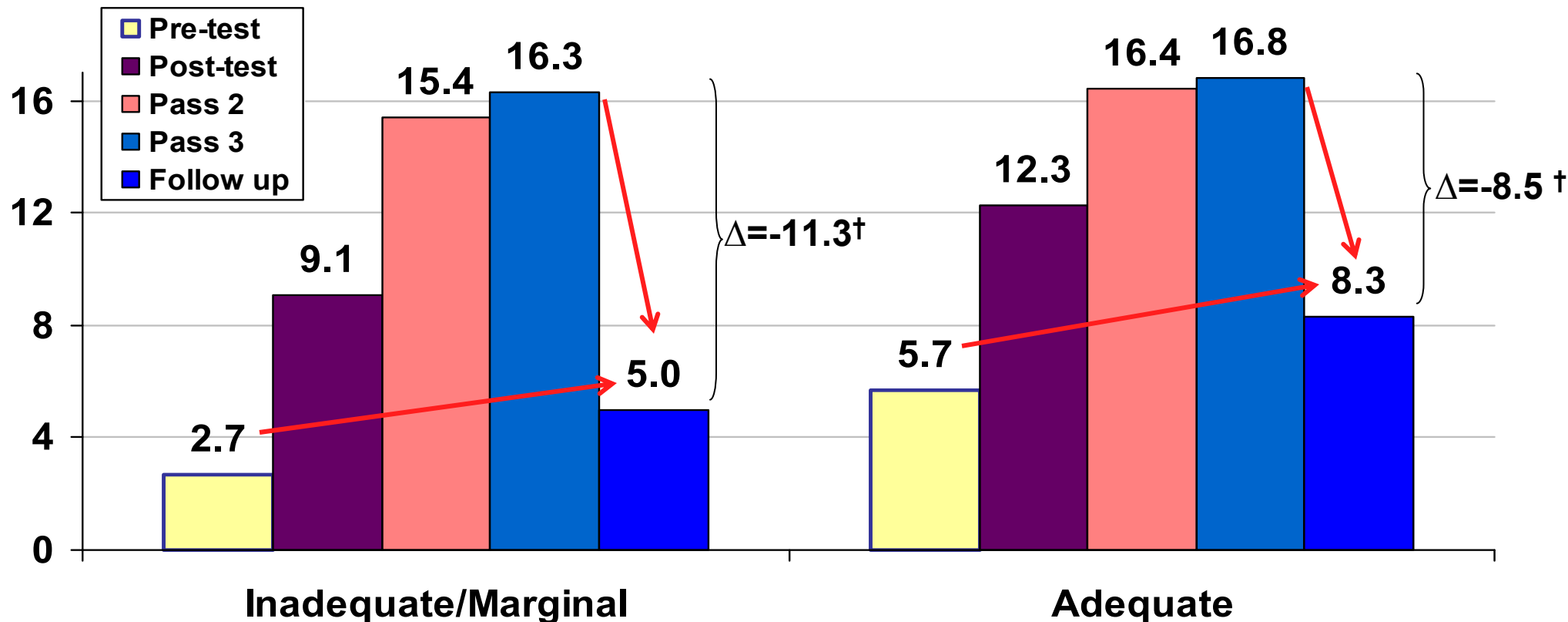
Teach Back Successful for Diabetes Education



[†]The absolute change from TTG pass 3 to follow-up, where the absolute change of the inadequate/marginal group (-11.3) is compared to the absolute change of the adequate group (-8.5); p-value<0.01.

But What About Long-Term Retention?

Table 4. Change in Knowledge Score for Patients in the MDEP + TTG Group

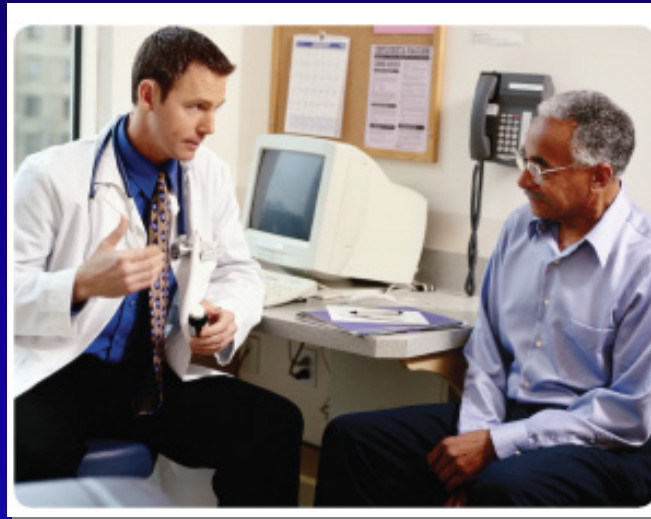


Beyond Teach Back

- How do we improve retention?
- Active learning and problem solving?
- Repetition/reinforcement outside of the healthcare setting?

Beyond the Office

The Status Quo: Most Info Given at Time of Visit



Pre-visit —————→ **Visit** —————→ **Post-visit**

A New Paradigm

- **Health needs assessed before a visit**
- **Based on this, patients given materials to prepare them for the discussion.**
 - **Print, multimedia, or both**
 - **Standardized information**
 - **Designed with patients to ensure clarity of words and concepts**
- **Office tools help providers communicate**
- **Patients sent home with summaries**
- **Automatic reminders sent to patients**

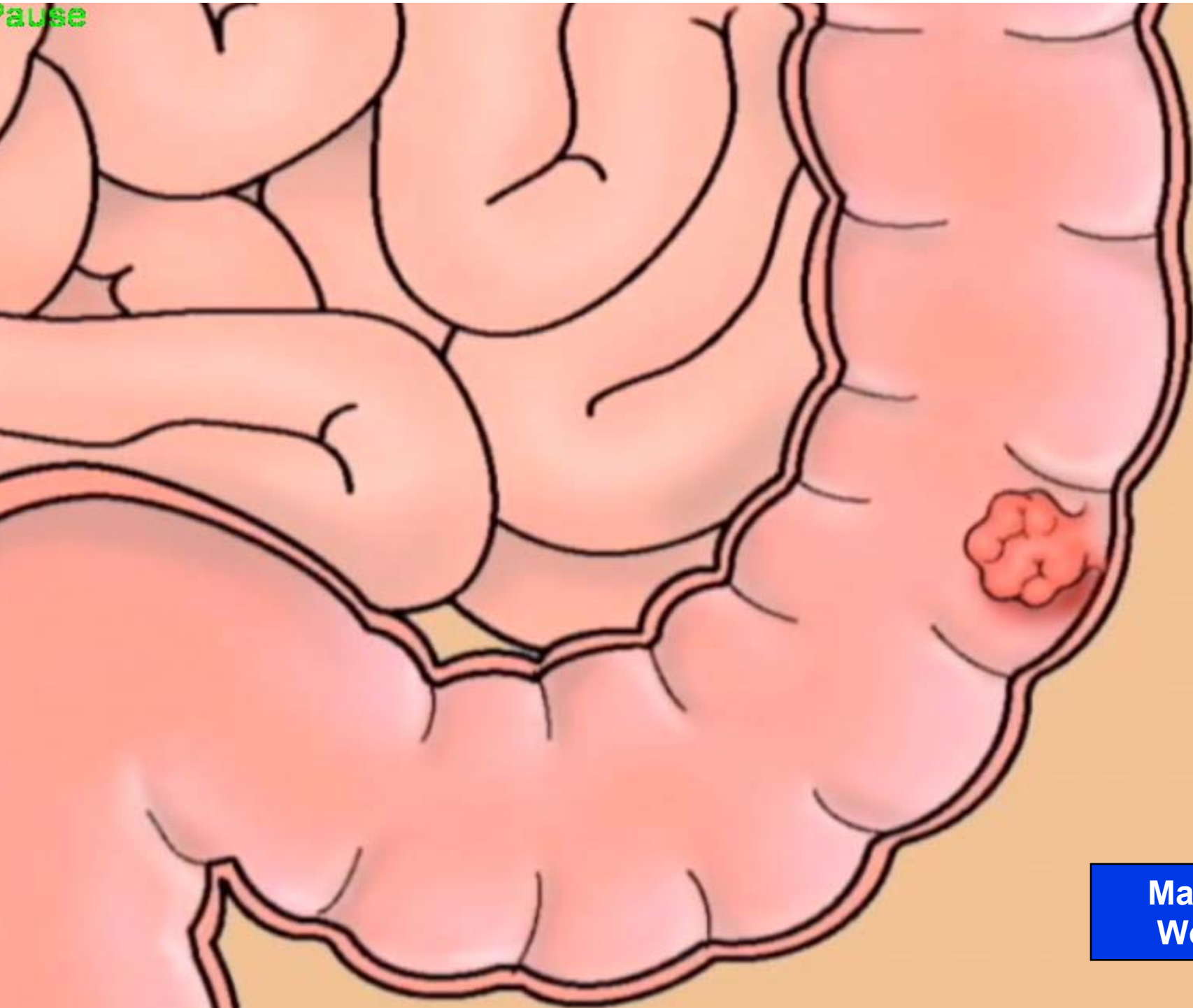
Before the Appointment

Dear Mr. Lucky,

Thank you for taking the time to complete your health check. This showed that you have never been screened for colon cancer. Screening for colon cancer can save your life.

Please come to your visit 15 minutes early. The nurse will show you a short video and answer your questions. Dr. Quick will also discuss this with you when you see her.

Pause



Makoul, Cameron,
Wolf, Baker, et al

Colorectal Cancer: Screening and Prevention



Understanding
Colorectal Cancer



Choosing the
Test for You



Stool Cards



Flex Sig



Colonoscopy

Produced by the Center for Communication and Medicine, Division of General Internal Medicine, Northwestern University Feinberg School of Medicine, with funding from the National Cancer Institute (1R21-CA-107242-01A1). Copyright © 2006 – Gregory Makoul PhD and David W. Baker MD, MPH - All rights reserved

SPANISH

EXIT

Choosing the Test for You



Stool Cards



Flex Sig



Colonoscopy

Purpose	Find blood in the stool	See inside rectum and lower part of colon	See inside rectum and all of colon
Timing	Every year	Every 5 years	Every 10 years
Location	Home	Doctor's office -or- Hospital	Hospital
Getting ready	Avoid certain foods and medicines	Use 2-4 enemas the morning of test	Take laxative medicine the night before test
Things to consider	Not all polyps bleed – can miss some	Not all polyps are in lower part of colon – can miss some	Requires medicine that makes you sleepy
	Not as accurate as other tests	Very small risk of the tube tearing colon (about 1 in 3,000)	Very small risk of the tube tearing colon (about 1 in 1,000)

[MENU](#)

[EXIT](#)

After the Appointment

Automated Reminders to Reinforce Understanding and Adherence

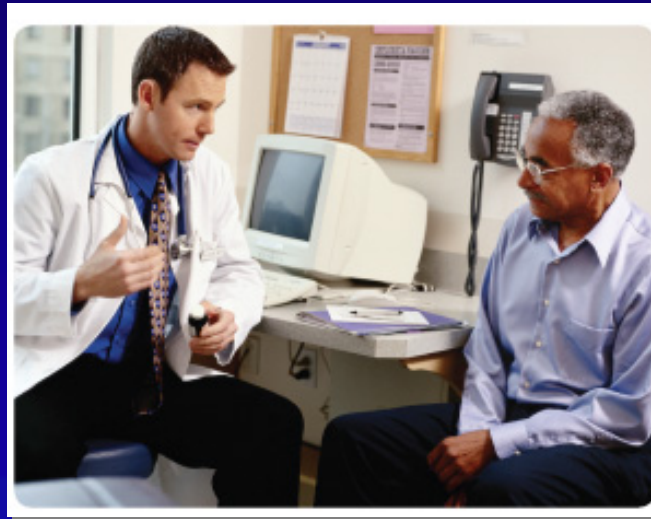
Dear Mr. Lucky,

I wanted to tell you again how important it is to be screened for colon cancer. Don't wait! Be sure to schedule your colonoscopy as soon as possible. Remember, this test could save your life.

Sincerely,

Dr. Quick

An Alternative Model



Pre-visit —————> **Visit** —————> **Post-visit**



Beyond Readability Formulas

or

**From Readability
To Usability**

Proxy Access

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My Health Record

[Current Health Issues](#)

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WELCOME

To your secure personal health management website.

What's New

- Access your After Visit Summaries. View your recent appointments and click on an appointment to review instructions and referrals.
- Caring for a parent or another adult? [Proxy Access](#) has been extended to adults age 18 and up.
- Have you been diagnosed with Diabetes? Ask your physician about how you can track your glucose levels with our new flowsheets.
- Protect yourself as Flu season approaches. Click [Schedule an Appointment](#), select Flu Shot, and find a time convenient for you.
- Proxy access is now available for all ages. Find out more on the [Proxy Access](#) page.

If you have questions about these enhancements or other functionality, please don't hesitate to contact us via the "Contact Us" feature or our support line at 847.425.3900.



[NorthShoreConnect Demo](#)



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YOUR HEALTH NEWS

U.S., Most States Get Failing Grades for Health Emergency Preparedness

Ginger Could Add Spice to Cancer Care

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Current Medications

 [printable page](#)

Below are your current medications, their dosage instructions, and the name of the provider who initially ordered each medication. You may request a prescription renewal if you have run out of refills on a prescription.

R_x FLECAINIDE 100 MG PO TABS

 [About This Medication](#)




Instructions: Take 1 tab by mouth two times per day.

Prescribed by [DAVID HWANG, MD](#) on 5/29/2008

[Request a renewal](#)

R_x LORATADINE (CLARITIN) 10 MG PO TABS


 [About This Medication](#)

Instructions: Take 1 tab by mouth once daily as needed

Prescribed by [DAVID HWANG, MD](#) on 5/29/2008

[Request a renewal](#)

R_x PRILOSEC 20 MG PO CPDR

 [About This Medication](#)

Instructions: 1 tablet by mouth twice daily

Prescribed by [DAVID HWANG, MD](#) on 5/2/2006

[Request a renewal](#)

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???



Search Results

Antiarrhythmic medications for fast heart rates

Example(s): Cordarone, Pacerone (amiodarone), Norpace (disopyramide), Tikosyn (dofetilide), Tambocor (flecainide), (procainamide), Rythmol (propafenone), (quinidine), Betapace (sotalol)

Antiarrhythmic medications for atrial fibrillation

Discusses drugs that help return heart to normal rhythm, maintain it, and reduce heart rate for those in atrial fibrillation. Lists generic and brand names like amiodarone (Cordarone), dofetilide (Tikosyn), and flecainide (Tambocor). Covers side effects.

Heart failure: Avoiding medicines that make symptoms worse

If you have heart failure, you need to be extra careful with medicines. Some can make your heart failure worse. Other medicines may not mix well with your heart failure drugs. This Actionset will help you learn which medicines you may need to avoid and what questions to ask your doctor or pharmacist. Key points Each time y

flecainide

Brand Name(s): Tambocor

How It Works

Antiarrhythmic medicines help return the heart to its [normal sinus rhythm](#), maintain the rhythm after it has been achieved, and/or reduce the heart rate while you are in atrial fibrillation. These medicines stabilize the heart muscle tissue. Antiarrhythmics such as amiodarone or sotalol also slow the heart rate by blocking impulses that pass through the [AV node](#) in the heart.

Why It Is Used

Antiarrhythmic medicines are used to convert [atrial fibrillation](#) to a normal rhythm. These medicines may be used before [electrical cardioversion](#) and may help maintain a normal heart rhythm after successful cardioversion. Ibutilide, another antiarrhythmic, may improve chances of successful cardioversion when used before cardioversion.

How Well It Works

Antiarrhythmic medicines can maintain a normal rhythm in 35% to 75% of the people who use them.^{[1](#)}

Side Effects

Antiarrhythmic medicines may increase the risk of developing a more severe irregular heart rate problem (ventricular tachycardia or ventricular fibrillation). Close monitoring while taking the medicine is important. The risk of side effects is greater with more severe underlying heart disease.



Mommy, you
should be on
Ibutilide for your
atrial fibrillation!



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► Medical Encyclopedia

Includes pictures and diagrams

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Spellings and definitions of medical words

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► Directories

Find doctors, dentists and hospitals

► Go Local

A service for finding local resources for health-related issues

Current Health News

- [Antibiotics in the ER: It's Often One-Size-Fits All](#)
- [Long-Term Back Pain Not Inevitable, Study Finds](#)
- [Nutrition Still Not 'A' Grade in U.S. Schools](#)
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[Know what to do about the flu!](#)

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ClinicalTrials.gov

Studies for new
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NIH SeniorHealth

Health information
for older adults



Surgery Videos

Videos of surgical
procedures



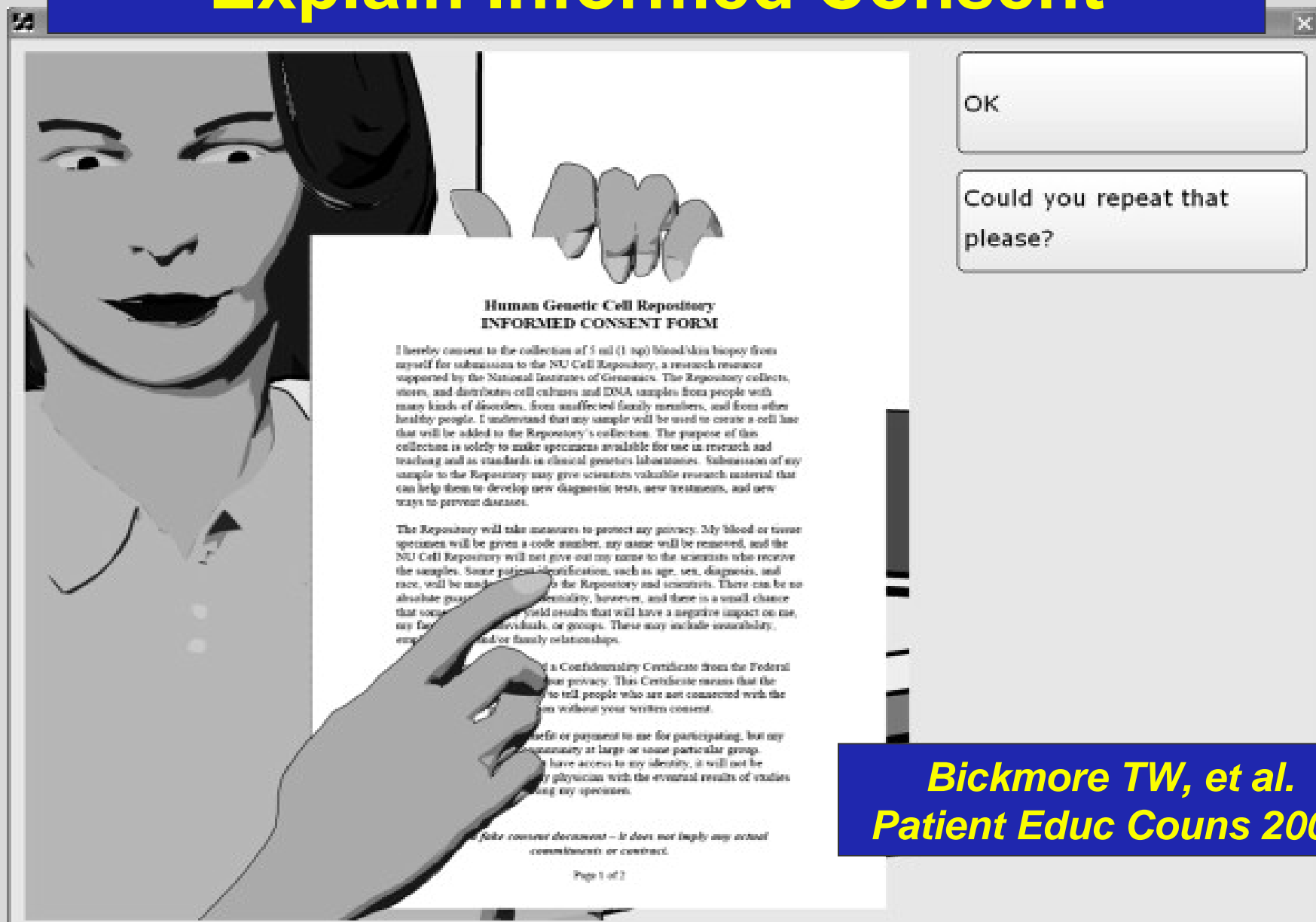
NEW

[What's New](#)

Challenges

- How do we demonstrate that patient portals and web sites are problematic for most Americans?
- How can we assess usability of these without direct usability testing, which is time consuming, expensive, and not feasible for all web sites
- Can we develop general guidelines for how to design these to make them more accessible?
- Can we use online instructional aids or other tools to help increase accessibility and usability?

Use of a Computer Agent to Explain Informed Consent



**Bickmore TW, et al.
Patient Educ Couns 2009**

Computerized “Agent” as Good as Human and Better than Self Study for Comprehension and Satisfaction

	Agent (<i>N</i> = 9)	Human (<i>N</i> = 9)	Self (<i>N</i> = 11)	Main effect sig.
Comprehension (% correct)	42.20 (20.33)	39.44 (12.86)	25.91 (11.36)	0.006
Satisfaction (1–7)	6.56 (1.01)	3.89 (2.47)	5.09 (1.70)	0.018
Likelihood to sign (1–7)	6.21 (1.30)	2.78 (2.39)	3.91 (2.43)	0.011
Pressure to sign (1–7)	2.11 (2.09)	2.00 (2.00)	1.55 (0.93)	0.719
Questions asked	1.12 (2.10)	1.22 (2.64)		0.967

