

Communications and Health Literacy 101

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Up to 1/2 of US population may be at risk for...

- Medical misunderstandings
- Mistakes
- Excess hospitalizations
- Poor health outcomes

Why are they at risk?

- Reliance on the written word for patient instruction
- Increasingly complex health system
 - More medications
 - More tests and procedures
 - Growing self-care requirements

Changes in the health care system

	<u>40 Years Ago</u>	<u>Today</u>
Treatment of Acute Myocardial Infarction	<ul style="list-style-type: none">• 4 - 6 weeks bed rest in hospital	<ul style="list-style-type: none">• 2-4 days in hospital (M&R Guidelines)
Available Prescription Drugs	<ul style="list-style-type: none">• 650	<ul style="list-style-type: none">• 10,000 +
Treatment of new onset diabetes	<ul style="list-style-type: none">• 3 weeks in hospital 2 hours a day of diabetic education classes	<ul style="list-style-type: none">• outpatient 0-3 hours diabetic education classes written materials internet telemedicine

Definitions:

General Literacy:

“ An individual’s ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential.”

National Literacy Act of 1991

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.”

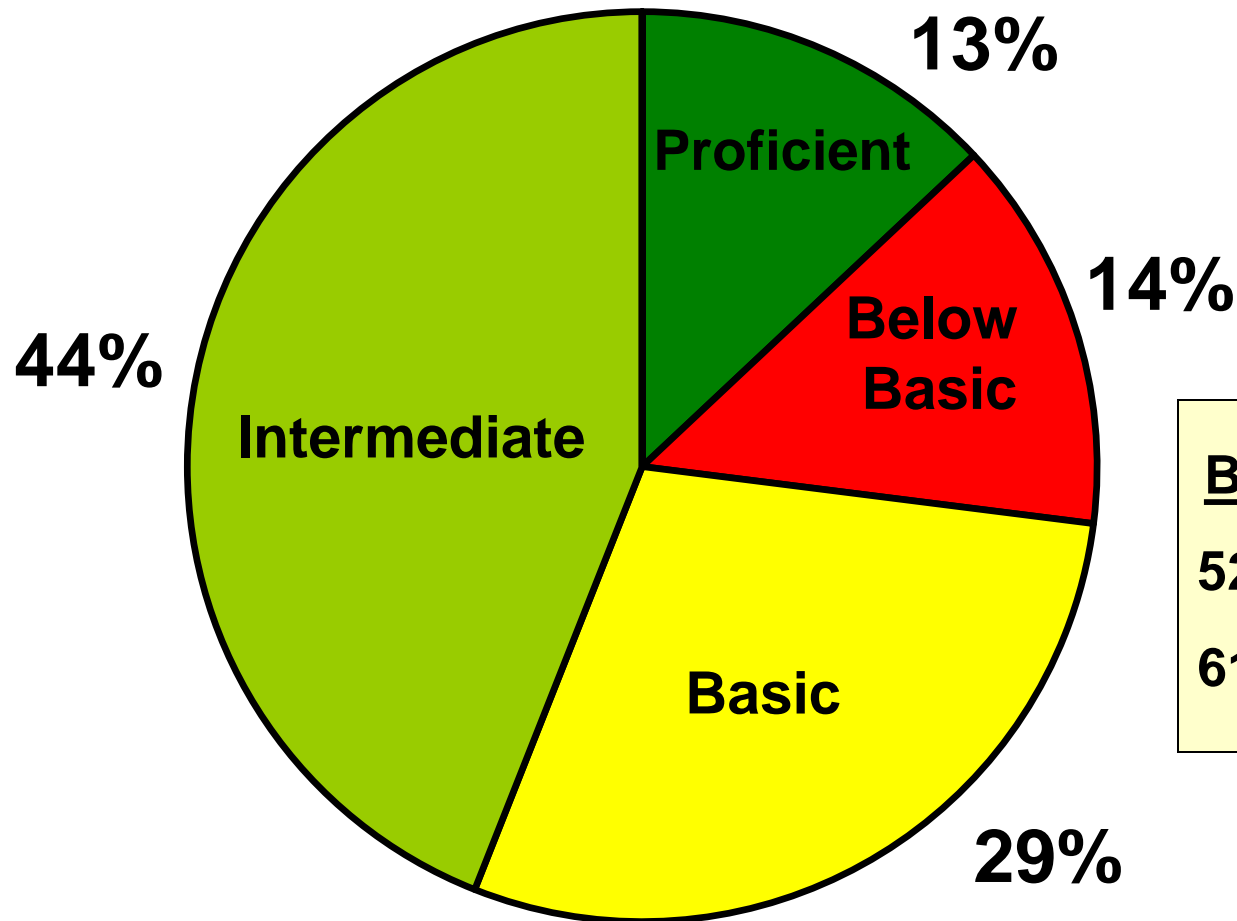
Healthy People 2010

Definitions:

Health Literacy:

- The ability to read, understand and **act upon** health care information
- Act upon- means actually do the work required in the care plan, reach the goals and sustain them through the normal constant changes of daily living.
- To “function on the job” of being a patient and “achieve one’s goals”...

2003 National Assessment of Adult Literacy



Basic or Below Basic

52% of H.S. Grads

61% of Adults ≥ 65

93 Million Adults have Basic or Below Basic Literacy

Sample Question

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

Parents and Teachers Evaluate Parental Involvement at Their School

Do you agree or disagree that...?

	Level of School		
	Elementary	Junior High	High School
Total			
percent agreeing			

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

% Correct

36% All Adults

0% < Basic

4% Basic

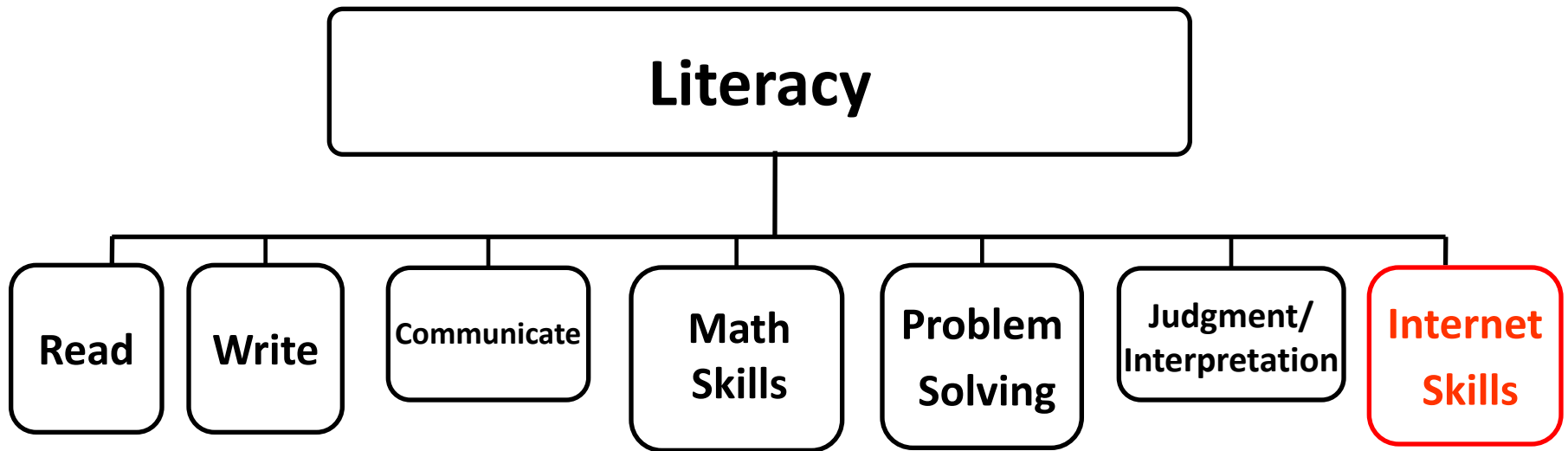
Sample of Tasks from NAAL

Skill Level	Health Literacy Tasks
Proficient	<ul style="list-style-type: none">•Calculate an employee's share of health insurance costs for a year, using a table that shows monthly costs.
Intermediate	<ul style="list-style-type: none">•Determine what time to take a Rx med from the label•Determine when child should get a vaccine based on chart of all childhood vaccines and ages.

Sample of Tasks from NAAL

Skill Level	Health Literacy Tasks
Basic	<ul style="list-style-type: none">• After reading a short simply written article about how hypertension lacks symptoms, explain why it is difficult for people to know if they have hypertension
Below Basic	<ul style="list-style-type: none">• Circle the date of a medical appointment on an appointment slip

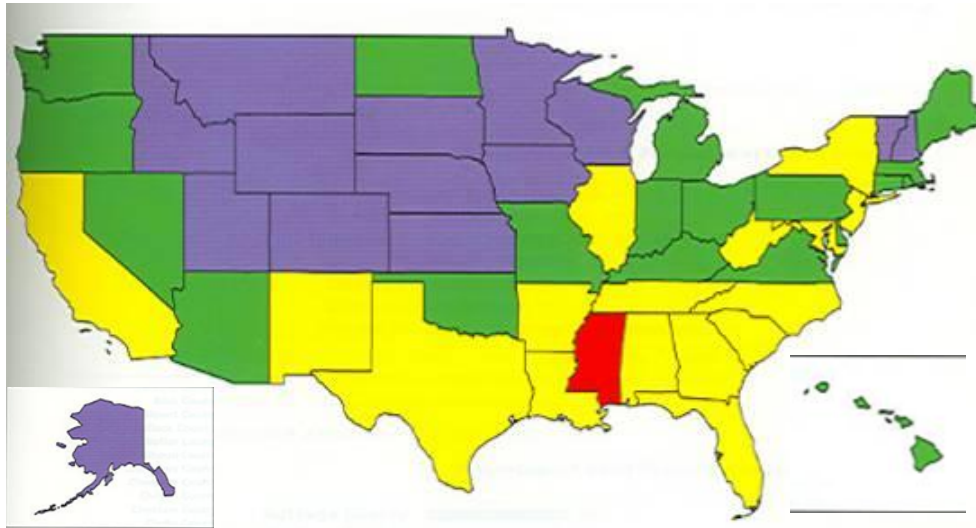
Literacy Definition (Requirement) Expands With Increasing Demands Of Society



“...at a level needed to function on the job and in society.”

Low Literacy is a National Problem

(National Adult Literacy Survey)



% Adults with Level 1
Literacy Skills

■ > 30%

■ 20% to 30%

■ 15% to 20%

■ < 15%

- 21% U.S. Adults are Level 1
- 48% level 1 and 2 – “lack sufficient literacy skills to function in society”
- Hispanic – 79%; African-American – 75%

What is it like?

- The following passage simulates what a reader with low general literacy sees on the printed page.
- Read the entire passage out loud.
- You have 1 minute to read.
- Hint: The words are written backwards and the first word is “cleaning”

**GNINAEELC – Ot erussa hgih ecnamrofrep,
yllacidoirep naelc eht epat sdaeh dna
natspac revenehw uoy eciton na
noitalumucca fo tsud dna nworb-red edixo
selcitrapp. Esu a nottoc baws denetsiom
htiw lyporposi lohocla. Eb erus on lohocla
sehcuot eht rebbur strap, sa ti sdnet ot yrd
dna yllautneve kcarc eht rebbur. Esu a
pmad tholc ro egnops ot naelc eht tenibac.
A dlim paos, ekil gnihsawhsid tnegreted,
lliw pleh evomer esaerg ro lio.**

What is it like?

- How do you clean the capstan?

Removing Barriers to Better, Safer Care:

- Patients have the right to understand health care information that is necessary for them to safely care for themselves,
- Healthcare professionals have a duty to provide information in simple, clear language and to check that patients have understood the information before ending the conversation.

But when they come into your office...

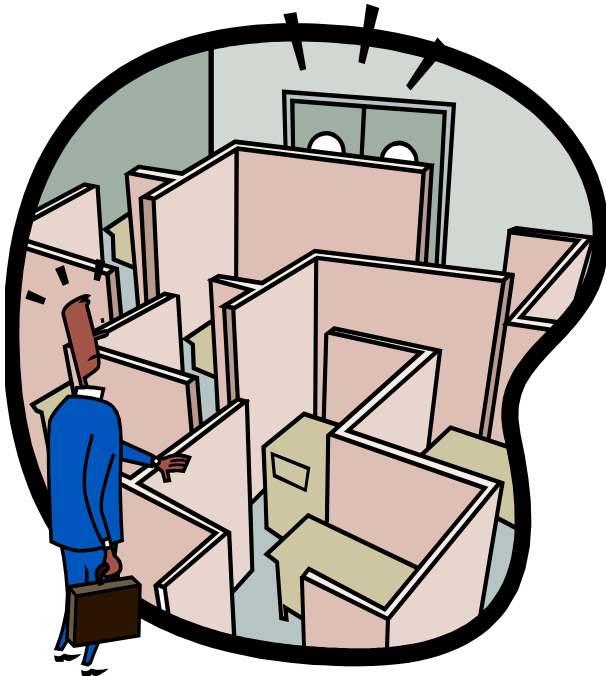
- No shows
- Disruptive – walk out
- After hours phone calls
- Going to the ED not the office
- How do you feel?

Designing a safer, shame-free health care environment

- Education of all staff
- System wide communication strategies
- Greater understanding of what the patient needs in order to function successfully

Patient's View of the Care Environment

- I want to see my doctor and nurse!
- I want to feel better.



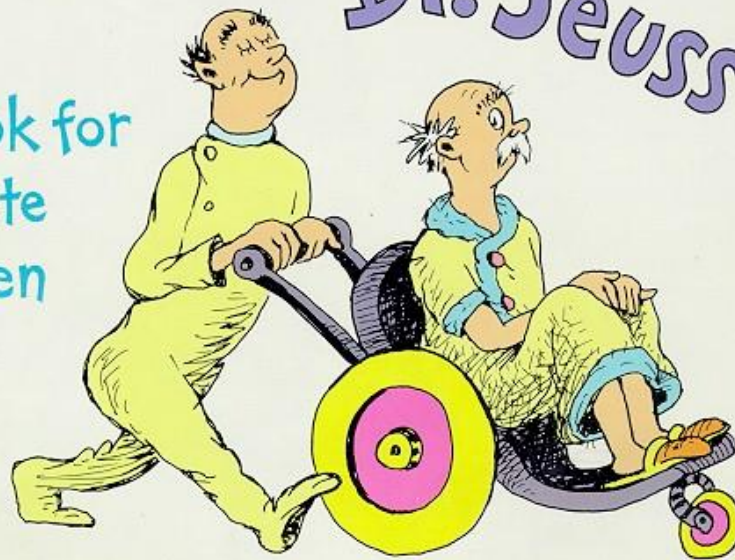
- You want me to do **WHAT?**
- Give medication Hx
- Make appointments
- Give informed consent
- Follow discharge instructions
- Read health education materials
- Complete insurance forms
- Pay my bill

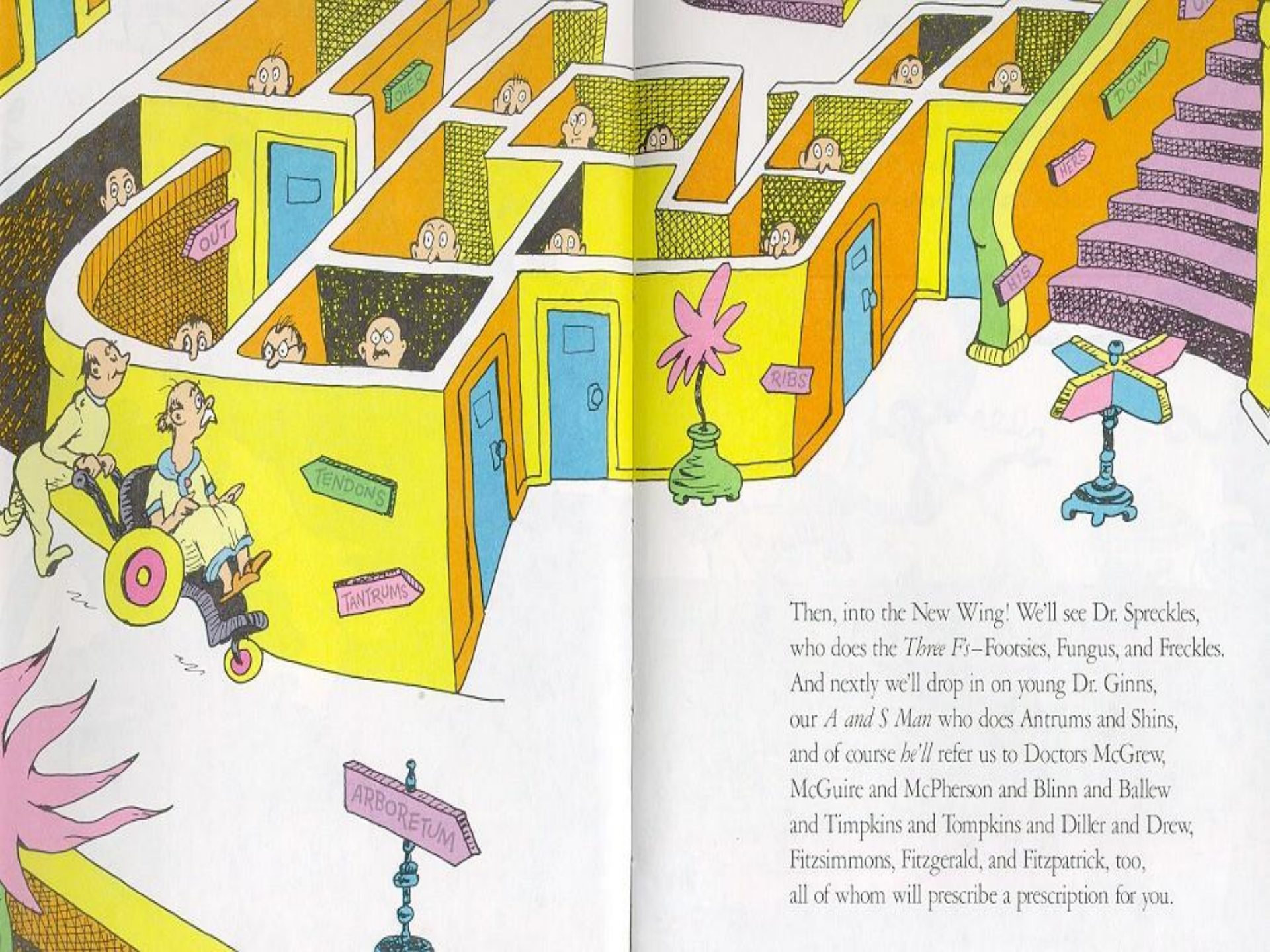


You're Only Old Once!

By
Dr. Seuss

A Book for
Obsolete
Children





Then, into the New Wing! We'll see Dr. Spreckles, who does the *Three Fs*—Footsies, Fungus, and Freckles. And nextly we'll drop in on young Dr. Ginns, our *A and S Man* who does Antrums and Shins, and of course *he'll* refer us to Doctors McGrew, McGuire and McPherson and Blinn and Ballew and Timpkins and Tompkins and Diller and Drew, Fitzsimmons, Fitzgerald, and Fitzpatrick, too, all of whom will prescribe a prescription for you.

How many physicians for each patient?

- Average for patients over 65 is 7
- Average for patients with 5 or more chronic conditions is 14 different, unrelated physicians and 40 office visits/year
- Berenson R. The medicare chronic care improvement program. Urban Institute, Washington, DC:2004. Available from:
<http://www.urban.org/publications/900714.html>

Multiple physicians, multiple communications

- Care coordination? Most rely on patient to coordinate own care.
- 50% of Medicare patients with serious chronic disease report different diagnoses for the same conditions
- 60% of caregivers of patients with chronic disease report that they have received conflicting advice.
- 30-60% of patients fail to take medications as prescribed

“All of whom will prescribe a prescription for you”

- Polypharmacy
- Rx container label most important continuing information for patient
- Variability of labeling a likely root cause of med errors
- New, standardized label might reduce medication errors.

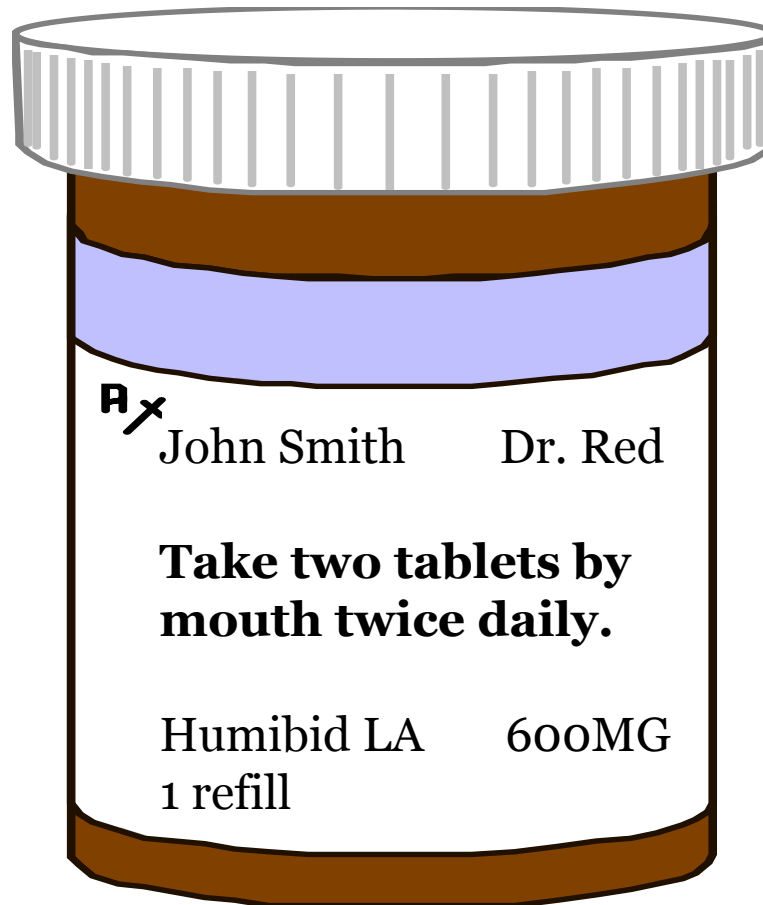
“How would you take this medicine?”

395 primary care patients in 3 states



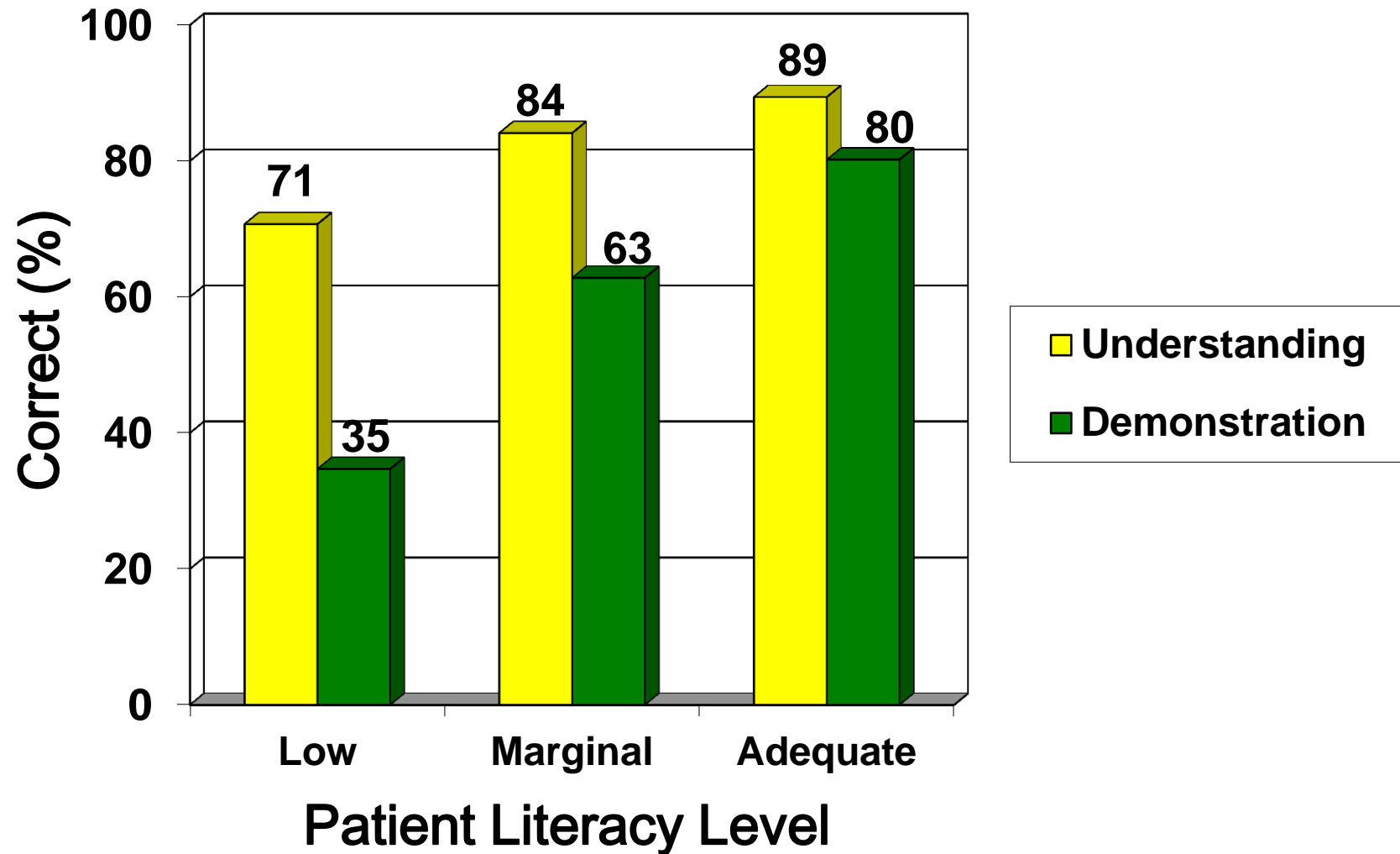
- **46%** did not understand instructions ≥ 1 labels
- **38%** with adequate literacy missed at least 1 label

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



Rates of Correct Understanding vs. Demonstration

“Take Two Tablets by Mouth Twice Daily”



Recommended one-on-one communication skills:

1. Conduct patient-centered visits
2. Explain things clearly in plain language
3. Focus on key messages and repeat
4. Use a “teach back” or “show me” technique to check for understanding
5. Use patient-friendly educational materials to enhance interaction.

For your Pill Drill you'll go to Room Six Sixty-three,
where a voice will instruct you, "Repeat after me..."

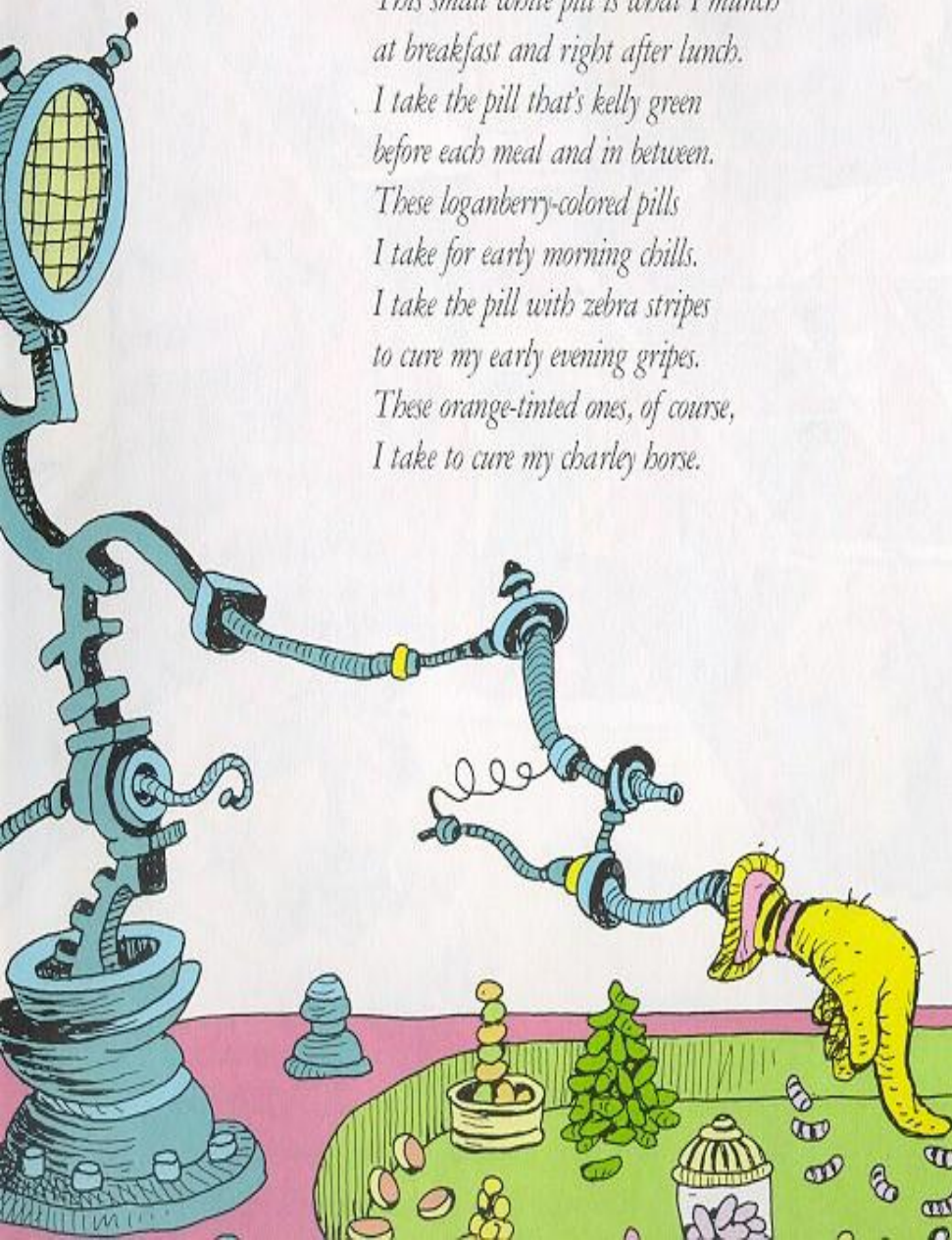
*This small white pill is what I munch
at breakfast and right after lunch.*

*I take the pill that's kelly green
before each meal and in between.*

*These loganberry-colored pills
I take for early morning chills.*

*I take the pill with zebra stripes
to cure my early evening gripes.*

*These orange-tinted ones, of course,
I take to cure my charley horse.*



*"I take three blues at half past eight
to slow my exhalation rate.*

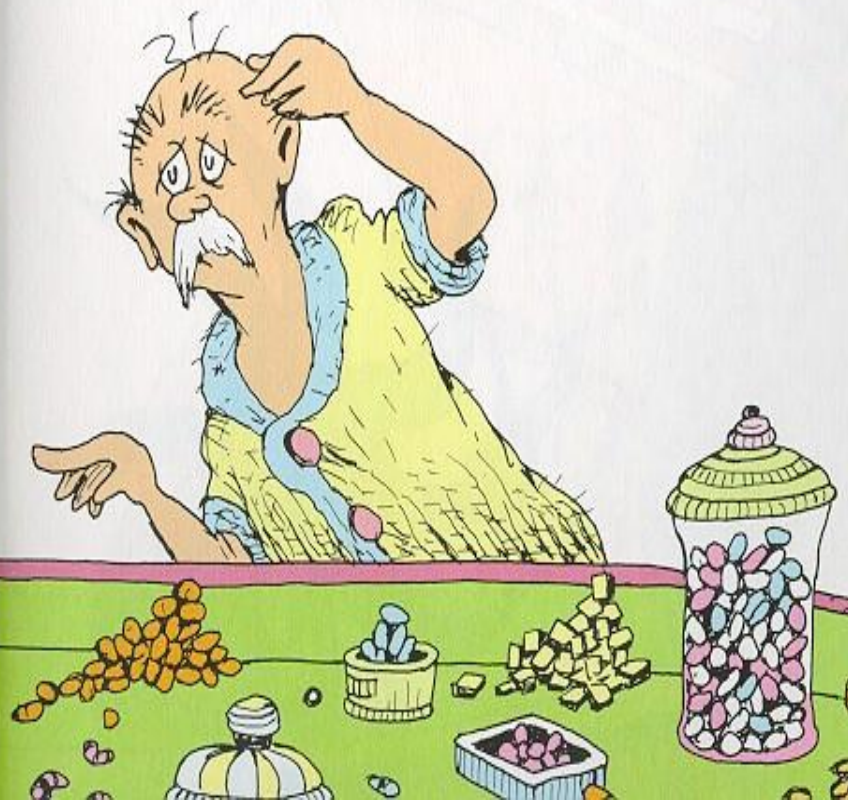
On alternate nights at nine p.m.

I swallow pinkies. Four of them.

*The reds, which make my eyebrows strong,
I eat like popcorn all day long.*

*The speckled browns are what I keep
beside my bed to help me sleep.*

*This long flat one is what I take
if I should die before I wake."*



Pill Drill – “Now repeat after me”

- “If I should die before I wake”...
- How can we design a safer environment in which the patient can function reliably?
- Can patient reach goals – reliability and sustainability
- Reliability – “what one can count upon not to fail in doing what is expected”.

Pill Drill – “Now repeat after me”

- “If I should die before I wake”...
- 51% of patients with CHF had a medication error in the first month post-hospitalization.
 - (Annals Intern Med.2012;157:1-10)
- How can we design a safer environment in which the patient can function reliably?
- Reliability – “what one can count upon not to fail in doing what is expected”.

High Reliability from the patient's perspective

- High reliability organizations “operate under very trying conditions all the time and yet manage to have fewer than their fair share of accidents”
- Teamwork, organizational mindfulness
- Patient must do the work at home, alone, without team or organization, in a natural, undesigned and chaotic environment.

Human Factors – how humans perform work

- the scientific discipline concerned with the understanding of interactions among humans and other elements of a system,
- Three major domains of human factors discipline:
- physical ergonomics concerned with physical activity— focus is on the physical characteristics of the person
- cognitive ergonomics concerned with mental processes— focus is on cognitive characteristics of the person
- organizational ergonomics concerned with socio-technical systems— focus is on the psychosocial characteristics of the person

Human Factors – how humans perform work

- physical ergonomics - e.g. work related musculoskeletal limitations
- cognitive ergonomics – e.g. mental workload, decision making, stress, training
- organizational ergonomics – e.g. communication, participatory design, new work models
- Handbook of Human Factors and Ergonomics in Health Care and Patient Safety; Edited by Pascale Carayon; Lawrence Erlbaum Associates; 2007

Distractions weaken patient confidence and cause confusion

- environmental,**
- emotional (such as fear and insecurity),**
- social (family dysfunctions and financial issues),**
- physical (fluctuating conditions, tremors, pain, nausea, fatigue) all can lead to confusion, error, and loss of confidence.**

Patient confidence or confusion: Can I do the work?

- Are there too many distractions?**
- Is this similar to what I have done before? Does it make sense to me?**
- If unclear, what action does make sense to me? What if I do it wrong?**
- Insecurity**
- What should I do?**

Case study –

(Courtesy of Steven Persell, MD)

- 68 year old woman with inadequate health literacy and newly diagnosed hypertension
- Also has depression and esophageal reflux
- Current medications
 - Fluoxetine 20 mg daily
 - Ranitidine 300 mg daily

Case study –

(Courtesy of Steven Persell, MD)

- Visit 1: 164/98, start HCTZ 12.5 mg Rx
- Visit 2: 150/91, raise to HCTZ 25 mg
- Visit 3: 147/85, add lisinopril 10 mg
- Visit 4: 145/83, increase lisinopril to 20 mg
- Visit 5: 151/85, “Which pills are you taking?”

Case Study

- Fluoxetine
- Ranitidine
- HCTZ
- Lisinopril



Fluoxetine 20 mg daily



Ranitidine 300mg



HCTZ 12.5 mg



HCTZ 25 mg



Lisinopril 10 mg



Lisinopril 20mg



Case study in human factors– The “Real” Pill Drill

- **Distractions?** (complexity, formulary demand for cheapest generic, multiple pinkish pills)
- **Is this similar to what I have done before? Does it make sense to me?** (cognitive processing, is cheaper really equivalent? is older, cheaper really better?)
- **If unclear, what action does make sense to me?** (Is smaller size really a larger dose?)
- **What if I do it wrong?** (fear, work around)
- **Insecurity**
- **What should I do?**

Human Factors, Patient Function and Self-Management Support

- **What do patients really need?** (help setting up a reliable, sustainable system at home, including navigation, emotional support, error management)
- **What do clinicians need to provide ?** (therapeutic alliance, interactive education with clear materials, coaching in basic navigational and organizational skills, repetition and reinforcement, and TIME!).

Human factors, Patient function and Self-Management Support

- . Which professionals? MD, RN, MSW, health educator, community worker?**
- . Teamwork, on-site or closely connected to physician office?**
- . Training? Credentialing?**

Human Factors and Behavior Change—what works?

- **Brief intervention/physician**
- **1 hour intensive 1-on-1/RN or PharmD**
- **Group visits/Lorig/16 hours**
- **1 hr intensive plus weekly phone education and interactive follow up preferred by patients with limited literacy to group visits.**

Example of successful “planned care” for patients with low literacy

- Professional planning – advance organizing, reduce info to key points**
- Preparation of materials to teach with and to provide a reliable, sustainable patient directed system of care at home.**

**DeWalt DA, Pignone M, Malone R et al. Development and pilot testing of a
a disease management program for low literacy patients with heart failure.**

***Patient Educ Couns* 2004;55:78-86.**

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

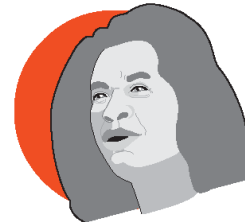
Good – You can walk easily with no shortness of breath



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 ☎³

Patient confidence or confusion

- **What is the work to be done?** (concrete step-by-step process at point of care)
- **Do I want to do it?** (therapeutic alliance, regular reporting by phone, visit)
- **What do I need to do the work?** (concrete steps, coaching with teach back, reliable system set up for home self-management, easy access to help via phone)

Patient confidence or confusion: Can I do the work?

- **Are there too many distractions?** (reviewed during coaching, if concerns, make a home visit)
- **Is this similar to what I have done before? Does it make sense to me?** (practice with coach and system/materials)
- **What if I do it wrong?** (materials cover, teach patient not to blame themselves, correct problem for next time)
- **Insecurity** (reduced by practice, system, supports)
- **What should I do?** (unexpected events can be handled through easy phone access).

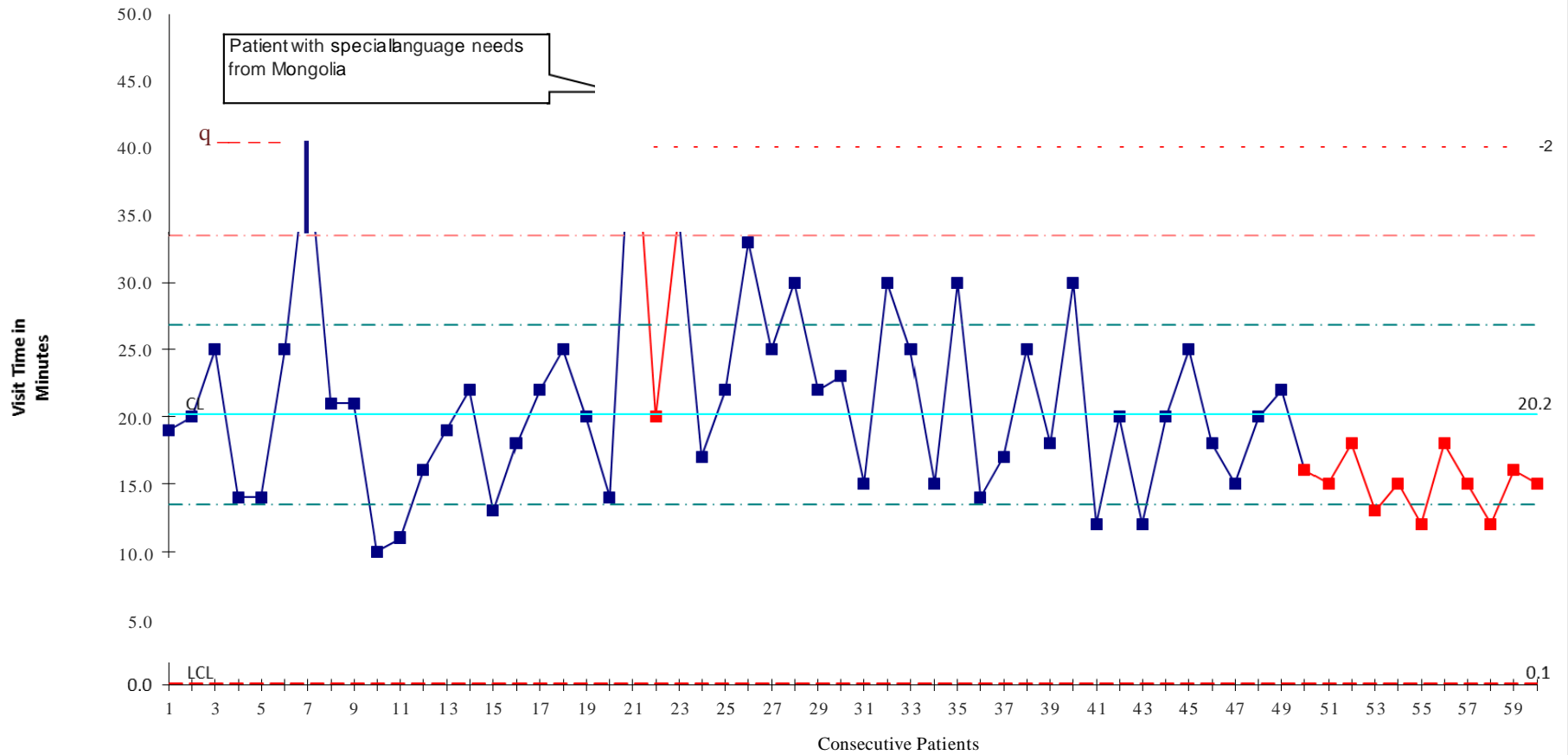
Patient Outcomes

- All patients in the intervention group had improved outcomes, but those with below 6th grade reading levels achieved better outcomes than patients with adequate literacy levels.
- Costs of \$37 per patient per month (includes materials, coaching time, system changes/support) above usual and customary.

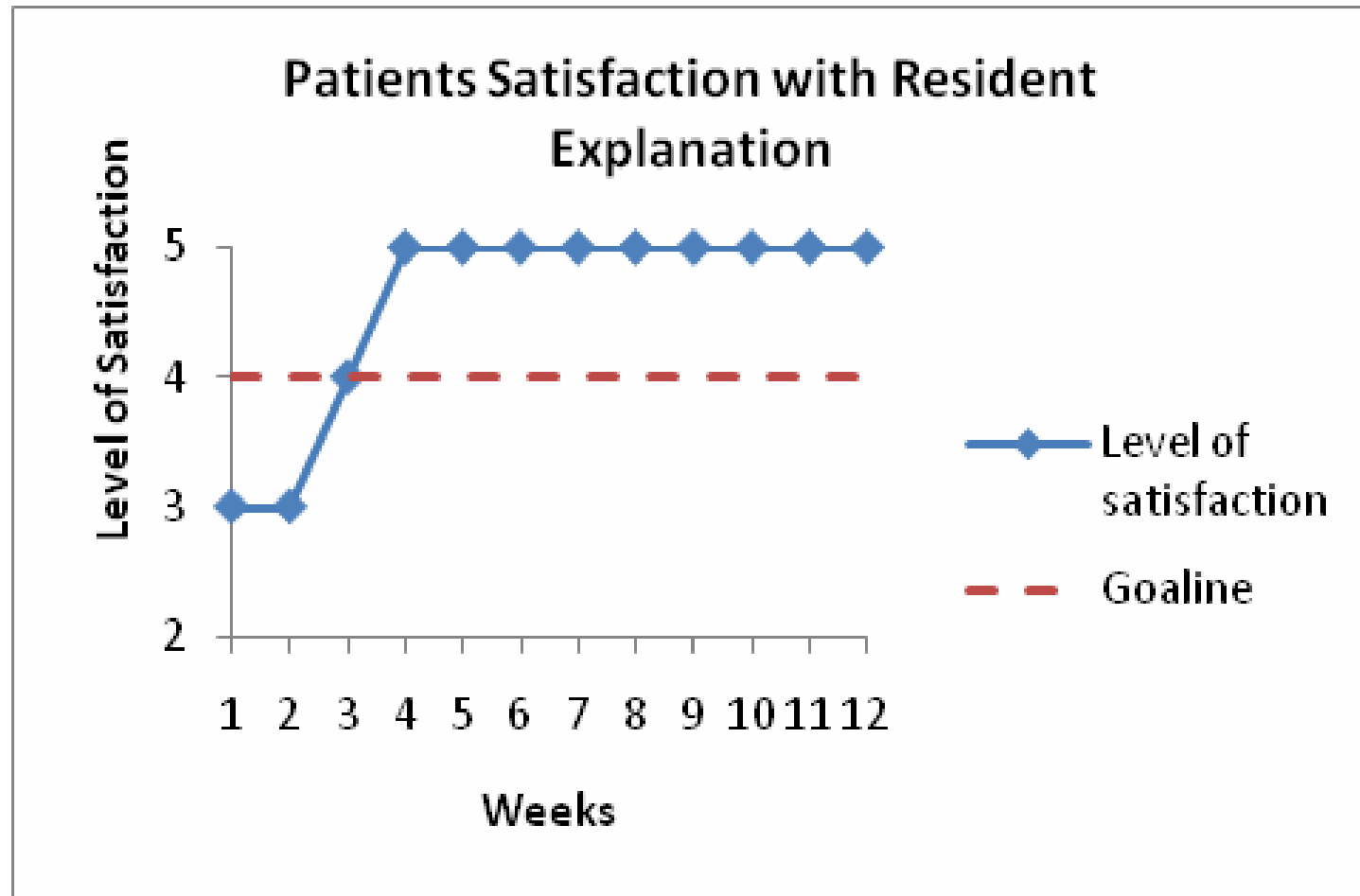
Perceived Barriers

- Teach Back takes too long, visit times will be prolonged
- Patients will not like being asked to repeat instructions, will feel insulted
- Staff will have to field complaints of parents/patients about being questioned

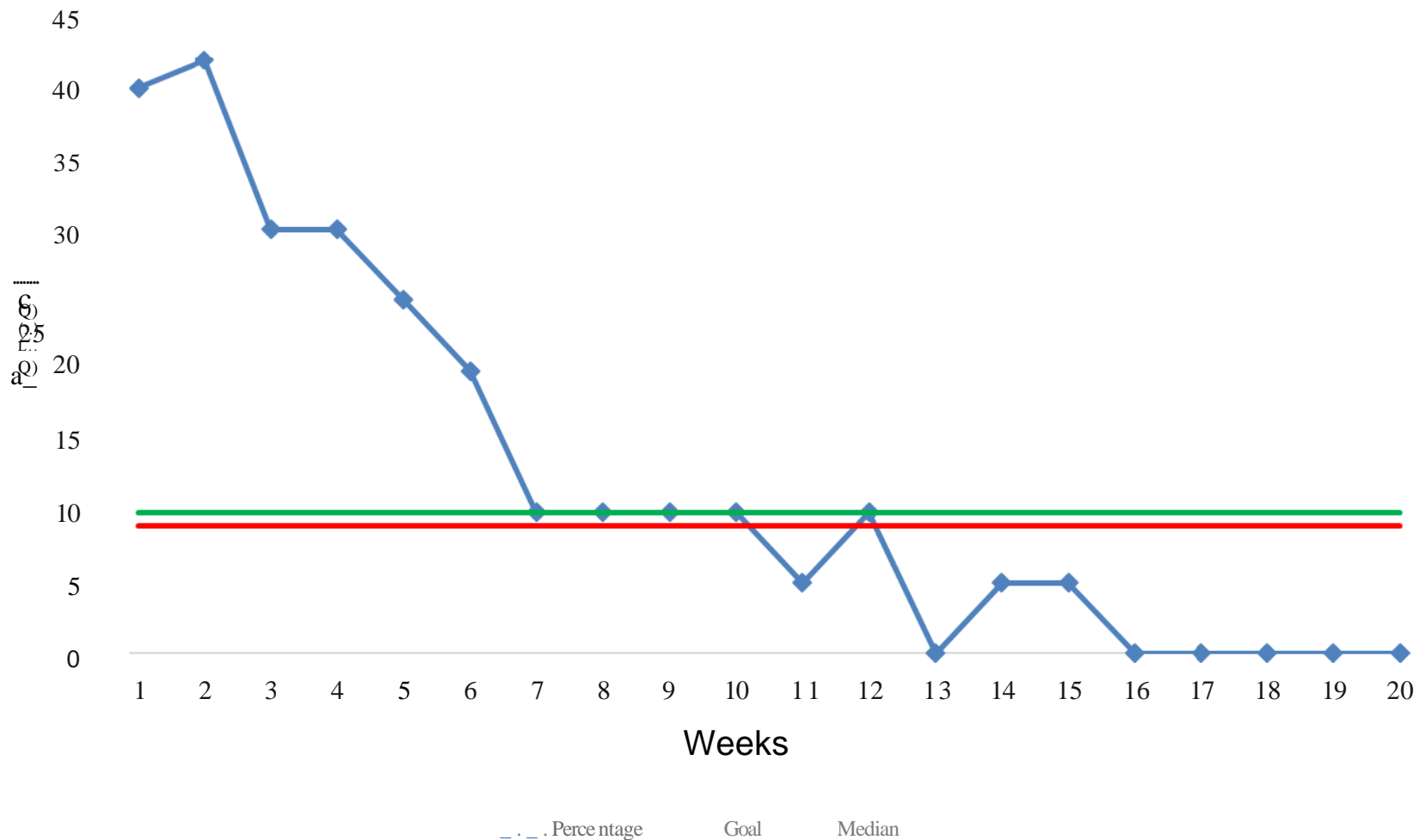
Impact of using Teach Back (TB) on Patient Visit Time



Patient Satisfaction



Percentage of Patients requiring Repeat Teach Back



Medication Error Most Common Medical Mistake

1.5 M *adverse events* (*patient error* >700,000)

- 2 out of 3 patients leave MD visit with Rx
- 3.9 Billion Rx filled in 2010
 - Up 50% - 60% in 10 years
- 82% adults take at least one med
- Elderly fill 20 Rx/year, see 8 physicians
- 1 in 6 pediatric Rx not dosed correctly
- >100,000 OTC meds (>600 contain acetaminophen)
- Most labels and inserts are in English only



U.S. Census Bureau, 2009; *PDR for Non-Prescription Drugs, Dietary Supplements and Herbs* (2007); IMS Health 2005; IOM 2006.

Financial Costs of Nonadherence to Medications

Non-adherence to medications is estimated to result in:

- 125,000 deaths per year from cardiovascular disease
- 10% of all hospital admissions; 25% of all nursing home admissions
- \$1.5 billion in lost patient earnings
- \$50 billion in lost productivity
- 112 million unnecessary medical visits
- An extra \$300 billion per year in excess spending

An Enhanced Label and “UMS”

<p>Do not drink alcoholic beverages while taking this medicine</p> <p>Carry or wear medical identification stating you are taking this medicine</p> <p>You should avoid prolonged or excessive exposure to direct and/or artificial sunlight while taking this medicine</p>	<p>Michael Wolf 04/23/71</p> <p>Glyburide 5mg</p> <p>Take for Diabetes</p>	<p>Rx #: 1234567 9/8/2009</p> <p>You have 11 refills 180 pills</p> <p>Discard after 9/8/2010</p>							
	<p>Take:</p> <p>2 pills in the morning 2 pills in the evening</p>	<p>Provider: RUTH PARKER, MD Emory Medical Center (414) 123-4567</p>							
	<table border="1"> <thead> <tr> <th>Morning 7-9 AM</th> <th>Noon 11-1 PM</th> <th>Evening 4-6 PM</th> <th>Bedtime 9-11 PM</th> </tr> </thead> <tbody> <tr> <td>2</td> <td></td> <td>2</td> <td></td> </tr> </tbody> </table>	Morning 7-9 AM	Noon 11-1 PM	Evening 4-6 PM	Bedtime 9-11 PM	2		2	
Morning 7-9 AM	Noon 11-1 PM	Evening 4-6 PM	Bedtime 9-11 PM						
2		2							

Correct Interpretation of Standard vs. Patient-Centered Label

N=500 (LSU & NW), Low Lit: 52%, AA: 64%, Avg. 3 Meds

Standard

*Take 2 pills by mouth
twice daily*

77%*

*Take 1 pill by mouth
3 times daily*

44%*

*p<.001

PCL

*Take 2 pills in the morning
and 2 pills at bedtime*

84%

*Take 1 pill in the morning,
1 pill at noon, and
1 pill in the evening*

91%

PCL & Graph

*Take 2 pills in the morning
and 2 pills at bedtime*

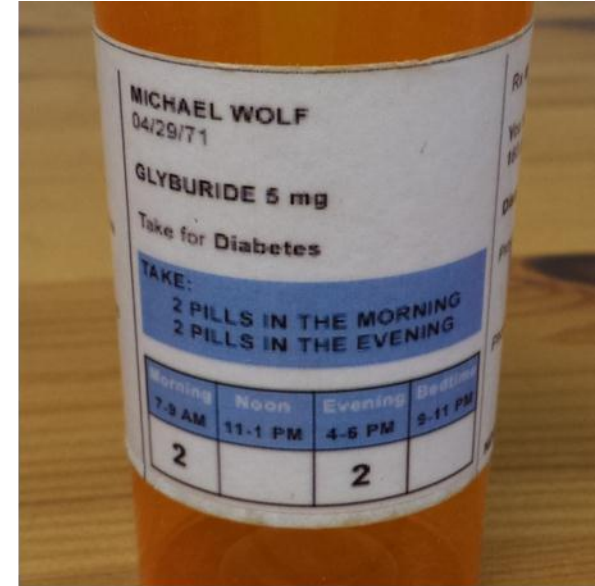
Morning	Noon	Evening	Bedtime
2	88%		2

*Take 1 pill in the morning,
1 pill at noon, and
1 pill in the evening*

Morning	Noon	Evening	Bedtime
1	1	1	91%

Wolf M ,Davis T, Parker R. Medical Care. 2011

Michael Wolf 04/29/71 Glyburide 5 mg Take for <u>Diabetes</u> <div style="background-color: yellow; padding: 5px;"> Take 2 pills at breakfast 2 pills at dinner </div> <table border="1" style="width: 100%; text-align: center;"> <tr> <th style="background-color: yellow;">Breakfast</th> <th style="background-color: yellow;">Lunch</th> <th style="background-color: yellow;">Dinner</th> <th style="background-color: yellow;">Bedtime</th> </tr> <tr> <td>2</td> <td></td> <td>2</td> <td></td> </tr> </table>		Breakfast	Lunch	Dinner	Bedtime	2		2		Rx#: 1234567 10/30/2008 You have 11 refills 180 pills Discard after 10/30/2009 Provider: Ruth Parker, MD Emory Medical Center (414) 123-4567 Pharmacy: NoVA ScriptsCentral 11445 Sunset Blvd. Reston, VA (713) 123-4567 NDC # 1234567	Important Do not drink alcohol. Limit your time in the sun.
Breakfast	Lunch	Dinner	Bedtime								
2		2									



RCT in 11 FQHCs.
429 pts w DM and/or HTN.
Average 5 meds
Mean age 52, 28% W,
39% low literacy

	Standard Label	PC Label
Understanding	59%	74%
Adherence (3 months)	30%	49%

State Board of Pharmacy in CA passed legislation for this label

Better Patient Outcomes

- ***We cannot change the human condition, but we can change the conditions under which humans work.***
- James Reason, Human error: models and management, *BMJ* 2000;320; 768-770

Snoitseuq?

Health literacy and patient safety: Help patients understand

<https://www.youtube.com/watch?v=cGtTZvxjyA>



type in Health Literacy

Useful Health Literacy Resources

AHRQ Toolkits

(Agency Healthcare Research and Quality)

- **Hospital Discharge**

Project RED (ReEngineered Discharge) (2013)

www.bu.edu/fammed/projectred/newtoolkit/

- **Informed Consent (2009)**

www.ahrq.gov/fund/informedconsent

- **Health Literacy Universal Precautions(2010)**

(clinic based system)

www.ahrq.gov/qual/literacy/

More Toolkits

Pharmacy Assessment Tools and Training

AHRQ (2007) *Strategies to improve communication between pharmacy staff and patients training program*

www.ahrq.gov/qual/pharmlit/pharmtrain.htm

Website Design

- **HHS (2010)** *Health literacy online a guide to writing and designing easy to use health web sites*

www.health.gov/healthliteracyonline/Web_Guide_Health_Lit_Online.pdf

Resources For Healthcare Organizations

Institute of Medicine (2012) Ten attributes of Health literacy
Healthcare Organizations

iom.edu/Global/Perspectives/2012/HealthLitAttributes.aspx

Health Literacy Environment of Hospitals & Health Centers
(2006) www.hsph.harvard.edu/healthliteracy/

The Joint Commission (2007) *What did the doctor say ?*
Improving health literacy to protect patient safety

National Quality Forum (2009) *Health Literacy a linchpin in*
achieving national goals for health and healthcare.

Communication Climate Assessment Tool (2010)

Wynia M: American Journal of Medical Quality

Health literacy Websites

CDC

- www.cdc.gov/healthliteracy
- www.cdc.gov/healthliteracy/pdf/simply_put.pdf

NIH

- www.nih.gov/icd/od/ocpl/resources/healthliteracyresearch.htm

UNC

- www.nchealthliteracy.org/

Rima Rudd (Harvard School of Public Health)

- www.hsph.harvard.edu/healthliteracy/

Helen Osborne

- www.healthliteracy.com/

Patient Education Development

CMS (2011) *Toolkit for making written materials clear and effective*

<https://www.cms.gov/writtenmaterialstoolkit/>

NCI (2003) *Clear and simple developing effective print materials for low literacy readers*

<http://www.cancer.gov/cancertopics/cancerlibrary/clear-and-simple/page1>

Arnold CL, Davis TC, Ohene Frempong J, et al: Assessment of newborn screening parent education materials. *Pediatrics*. 2006;117:320-5.

Seligman HK, Wallace AS, DeWalt DA, et al: Developing low-literacy patient educational materials to facilitate behavior change. *Am J Health Behav*. 2007 Sep-Oct;31 Suppl 1:S69-78.

National and State Literacy & Health Data

National Assessment of Adult Literacy

- <http://nces.ed.gov/naal/factsheets.asp>
- <http://nces.ed.gov/naal/saal.asp>

United Health Foundation

- www.americashealthrankings.org/rankings

Annie E. Casey Foundation

- <http://datacenter.kidscount.org/>

CDC

- www.cdc.gov/healthliteracy/statedata/index.html

Helpful References

- **Institute of Medicine** (2004) *Health Literacy: A Prescription to End Confusion*. In Nielson-Bohlman L, Panzer A, Kindig DA, eds. Washington, DC: National Academy Press
- Schwartzberg JG (2005) *Understanding health literacy: Implications for medicine and public health*. **AMA** Press
- Weiss BD (2003) *Health Literacy: A Manual for Clinicians*. **AMA** Foundation
- Doak CC (1996) *Teaching Patients with Low-Literacy Skills, 2nd ed*. JB Lippincott
- **US DHHS** (2010) National Action Plan to Improve Health Literacy www.health.gov/communication/HLactionplan
- **The Joint Commission** (2008) Strategies for Improving Health Literacy from The Joint Commission Perspectives on Patient Safety. The Joint Commission: Oakbrook Terrace, Illinois