“Health Literacy”: what is it, why does it matter, what to do about it?

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Official definition – (as you know because it's in the resolution)

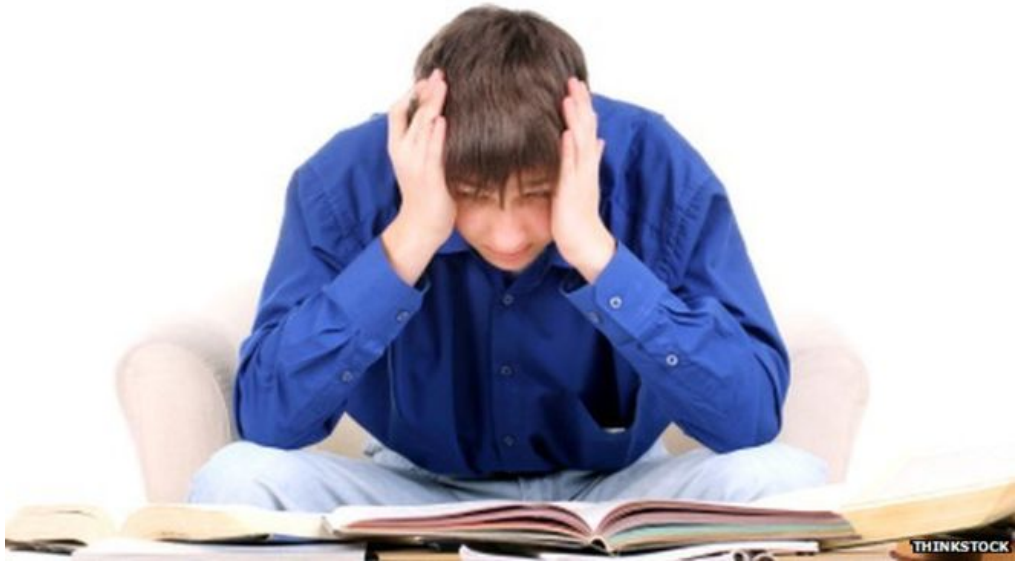
"The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."

-- Healthy People 2010

- Is health literacy entirely a property of individuals and their capacities?
- What information (and services) do people actually need?
- How do they need to process it?
- What are "appropriate" decisions?

The first order model

- Health literacy = basic reading skills, sometimes with numeric skills added.
- Operationalized by simple tests, not even necessarily specifically related to health or health care.



TOFHLA

Test of Functional Health Literacy in Adults

- Series of health-related reading tasks that measure numeracy and reading comprehension
- Patients asked to read passages in which every 5th to 7th word has been deleted and to insert the correct word from a choice of four words

REALM

Rapid Estimate of Adult Literacy in Medicine

- Word recognition test
- Quick and easy to administer
- Participant says each word out loud. Scored on number **pronounced** correctly

  61-66: not low lit
  45-60: grade 7-8
  19-44: grade 4-6
  0-18: grade 3 or below
- Doesn't matter if they know the word's meaning

Davis T, Long S, et al
Rapid estimate of adult literacy in medicine: a shortened screening instrument
Fam Med. 1993; 25: 391-395

fat	fatigue	allergic
flu	pelvic	menstrual
pill	jaundice	testicle
dose	infection	colitis
eye	exercise	emergency
stress	behavior	medication
smear	prescription	occupation
nerves	notify	sexually
germs	gallbladder	alcoholism
meals	calories	irritation
disease	depression	constipation
cancer	miscarriage	gonorrhea
caffeine	pregnancy	inflammatory
attack	arthritis	diabetes
kidney	nutrition	hepatitis
hormones	menopause	antibiotics
herpes	appendix	diagnosis
seizure	abnormal	potassium
bowel	syphilis	anemia
asthma	hemorrhoids	obesity
rectal	nausea	osteoporosis
incest	directed	impetigo

Research based on REALM and TOFHLA

- Generally finds that low scores are associated with worse health outcomes, lower medication adherence, and less knowledge but –
  - Results are somewhat inconsistent (e.g., some studies find **better** antiretroviral adherence with lower literacy, or no relationship)
  - Associations may not be strong, i.e. some people with low literacy have more accurate knowledge than some with high literacy.
  - Hard to disentangle education/SES, LEP, other confounders.
- Bottom line: It's more complicated.

National Assessment of Adult Literacy

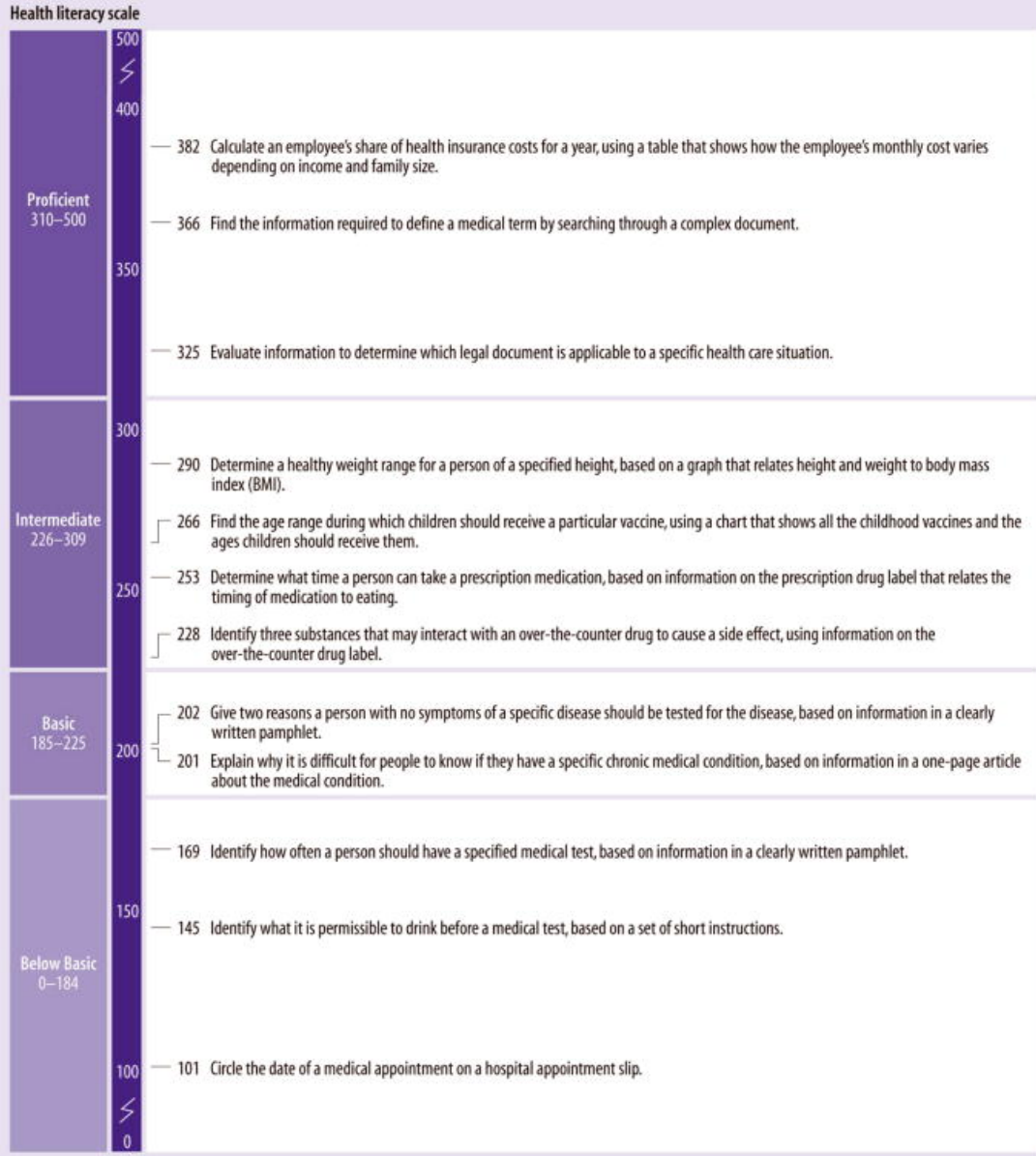
Measured more specific task competencies

But, no assessment of health outcomes

Does analyze demographic patterns of assessed health literacy

Kutner, M., Greenberg, E., Jin,Y., and Paulsen, C. (2006). *The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy* (NCES 2006–483).U.S.Department of Education.Washington, DC: National Center for Education Statistics.

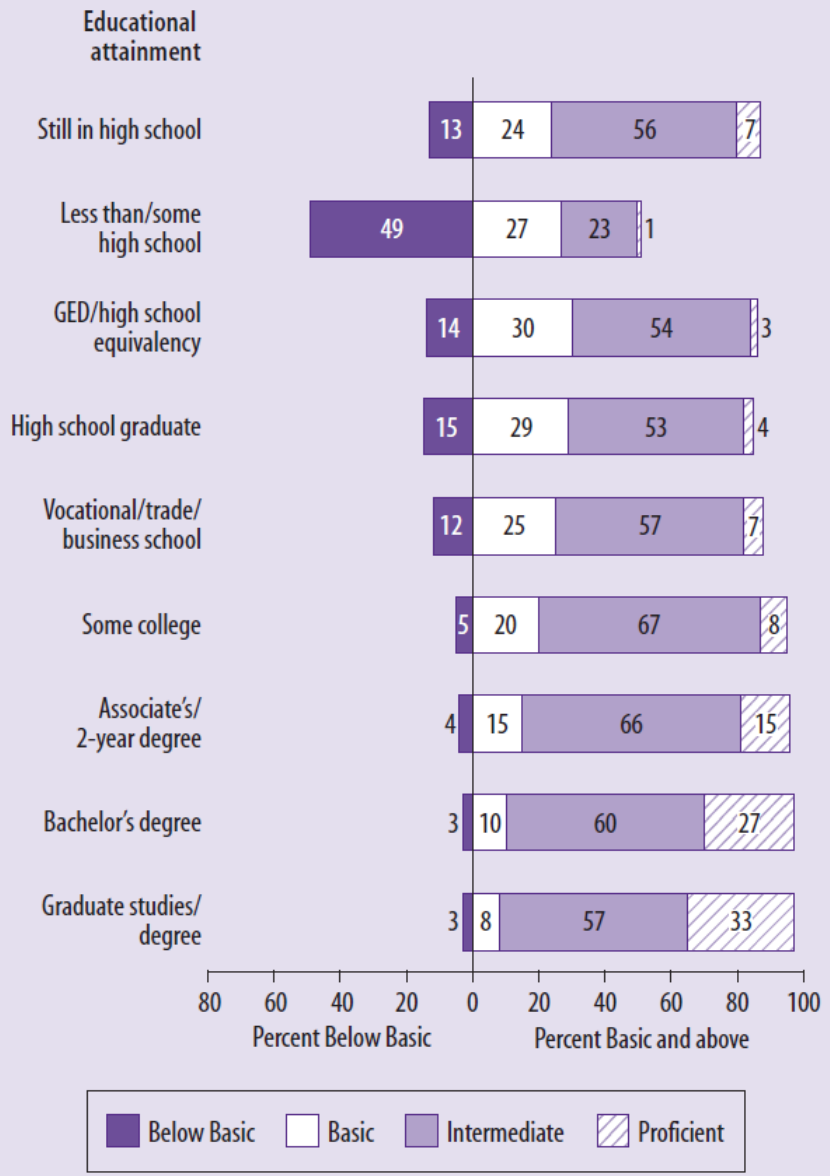
Figure 1-1. Difficulty of selected health literacy tasks: 2003



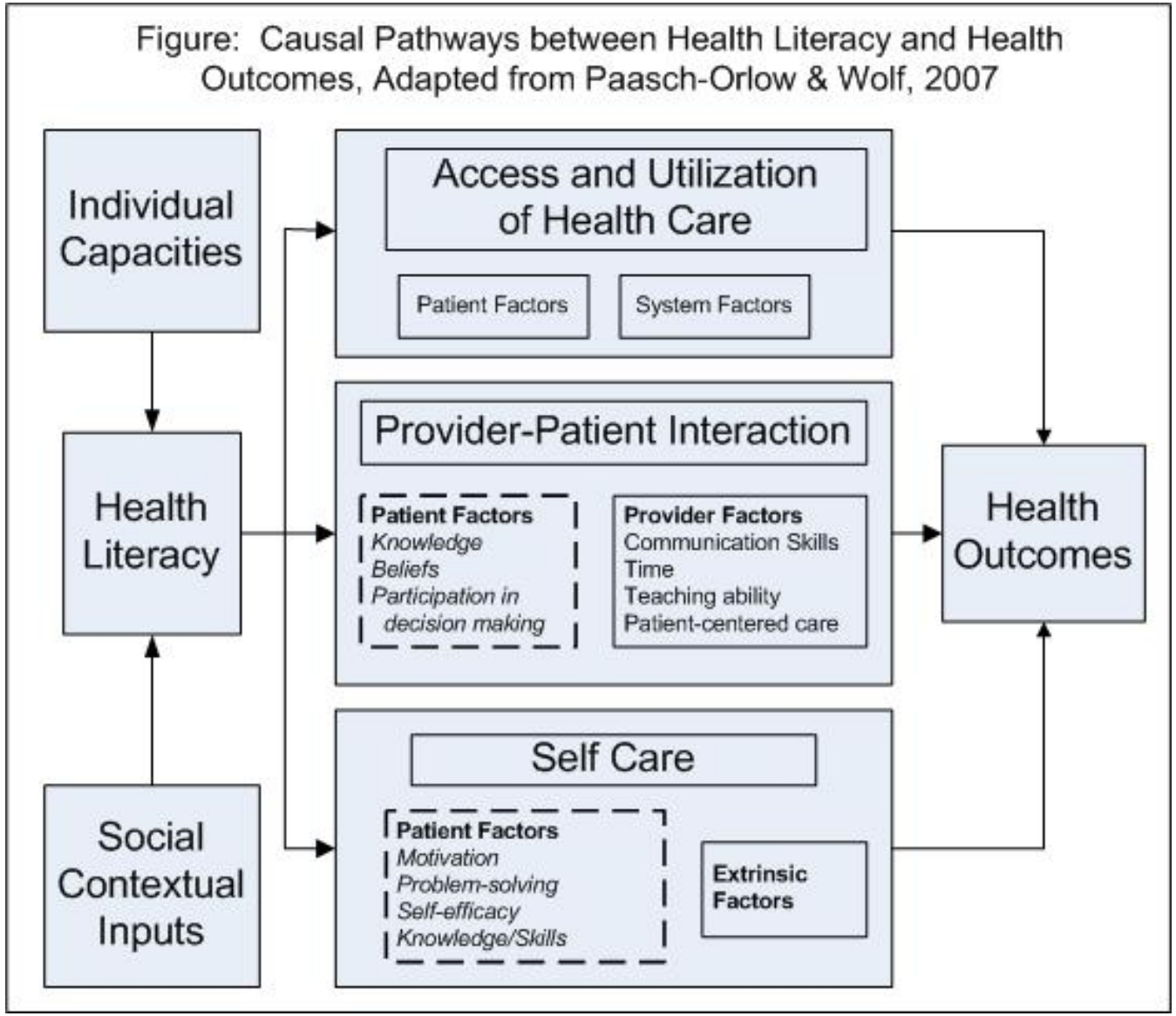
NOTE: The position of a question on the scale represents the average scale score attained by adults who had a 67 percent probability of successfully answering the question. Only selected questions are presented. Scale score ranges for performance levels are referenced on the figure.
SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy.

Figure 2-4. Average health literacy scores of adults, by race/ethnicity: 2003

Figure 2-9. Percentage of adults in each health literacy level, by highest educational attainment: 2003



A fuller concept



Related concept of “patient activation”

“Understanding one’s role in the care process and having the knowledge, skill, and confidence to manage one’s health and health care.”*

“Engagement” = activation + interventions + resulting behaviors

≠ adherence or compliance – or is it?

* Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure: conceptualizing and measuring activation in patients and consumers. Health Serv Res 2004;39 (4 Pt 1)

The issues of “patient activation”

The social production of health
(before doctors come into the picture)

When to seek medical services; where or from whom

Communicating symptoms, problems, goals to providers

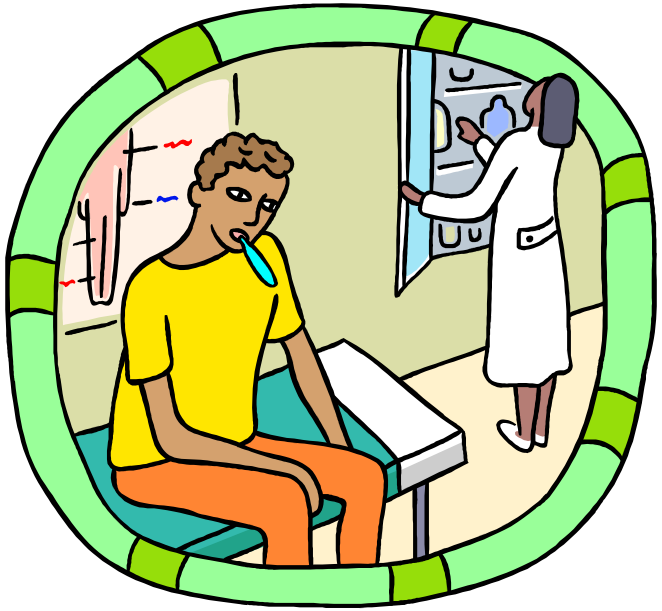
Understanding (and accepting?) diagnosis

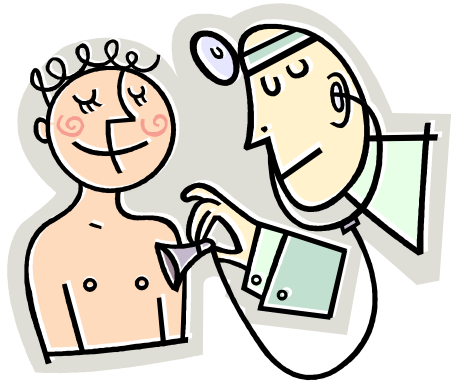
Making decisions about treatment consistent with patient preferences, circumstances, goals

Self care/self management behavior (adherence?)

The changing physician-patient relationship?

1950s: Benevolent Paternalism -> 1980s: Patient Centeredness -> 1990s: Shared Decision Making -> 2000s: Concordance





These evolving paradigms may or may not have much to do with reality

The importance of numeracy

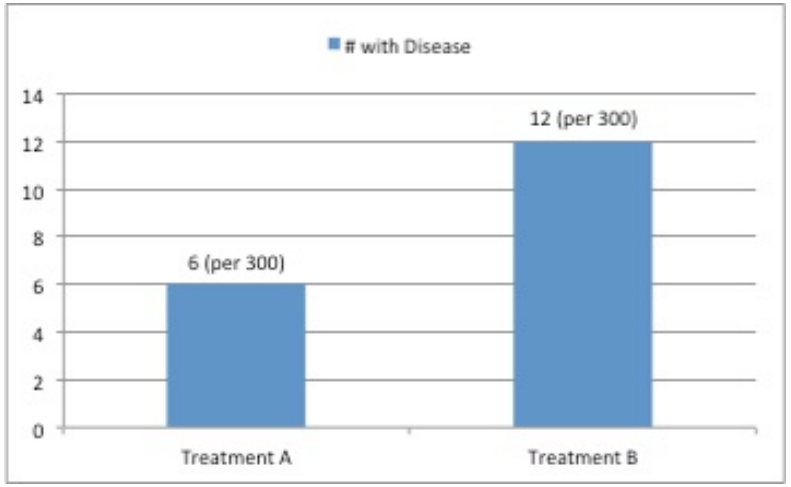
- “Shared Decision Making” – Patients asked to weigh risks, burdens and benefits, make choices based on personal preferences
  - These mostly depend on probabilistic thinking

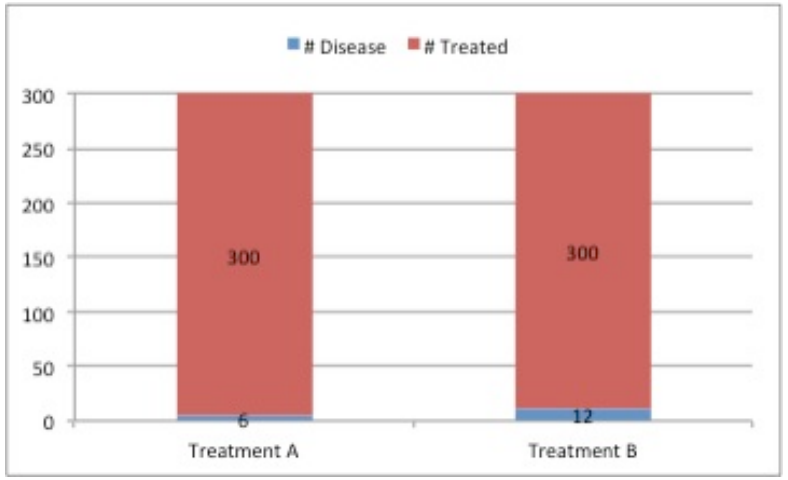
Loss vs. gain framing

	Framing	Treatment A	Treatment B
Chosen by 72%	Positive	"Saves 200 lives"	"A 33% chance of saving all 600 people, 66% possibility of saving no one."
Chosen by 22%	Negative	"400 people will die"	"A 33% chance that no people will die, 66% probability that all 600 will die."

Tversky and Kahneman, 1981

Absolute vs. Relative Risk





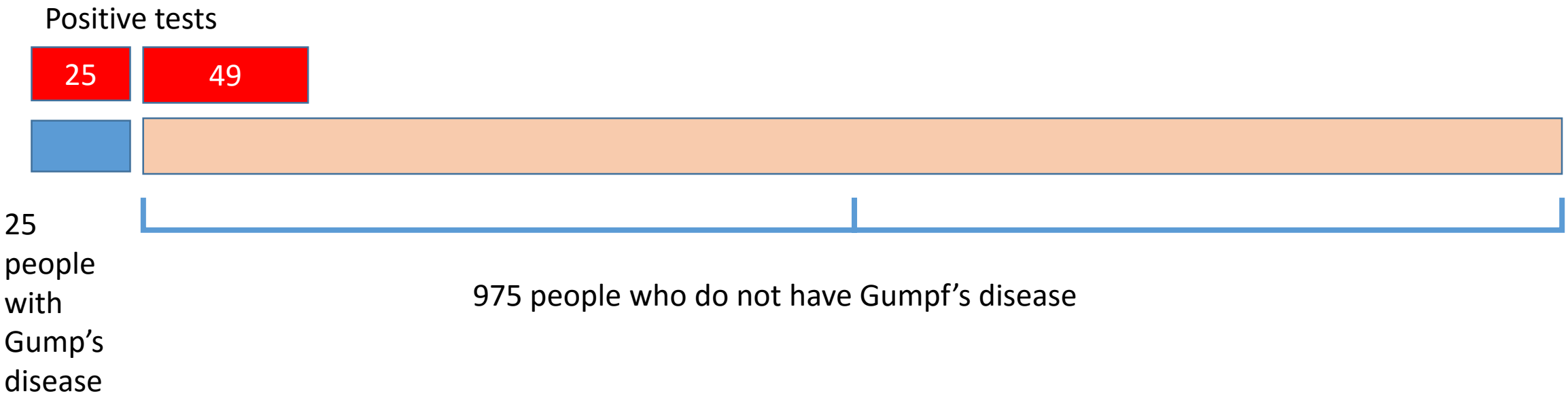
Bayes Theorem

Suppose there is test for Gumpf's disease.

It is 95% "specific": Only 5% of people who don't have Gumpf's disease will test positive.

Your test is positive. (Oh no!)

What is the probability you have Gumpf's disease?



Even though you tested positive, and the test is 95% specific, your chance of having the disease is only about 1/3.

What light can our own research shed?

Laws MB, Wilson I, Bowser DM, Kerr S. Taking anti-retroviral medications for HIV infection: learning from patients' stories. *Journal of Gen Internal Medicine,* 15;12:848-858, 2000

In 2000, ARV regimens were complex; equivalent to typical polypharmacy of elderly with chronic conditions today

Semi-structured interviews with 52 people with ARV prescriptions

Most initially said they were adherent; but then went on to report such behaviors as ceasing treatment, sleeping through doses, skipping due to side effects, and following highly asymmetric schedules.

Sometimes I do holidays of 3 or 4 days because I like to get free from all drugs.

Does not consider this to be non-adherence

I've been taking my medications the right way.

Does not take when misses meals; does not take when out of house and doesn't trust the water; takes at 6:00 am and 3:00 pm

Well, it isn't hard for me. Really I have no problem.

Sometimes forgets morning dose (incl. this morning); has run out 2 or 3 times in last year; forgets 3 times a week; finally says it's more important not to worry than to be adherent.

Adherence means 3 times a day. I take them whenever I eat, sometimes 2 hours apart. (He gets in all 3 doses between 10:00 am and 6:00 pm.)

“They’re not spaced like they’re supposed to, but I know enough about the medication where I know they still overlap. These medications don’t flush out of your system in 8 hours like they make people believe.”

ARV regimens are much easier to take nowadays. However, my current interviews still find that some people still have rationales that conflict with medical wisdom.

Rifkin DE, Laws MB, Rao M, Balakrishnan VS, Sarnak MH, Wilson IB. Medication Adherence Behavior and Priorities Among Older Adults with Chronic Kidney Disease: A Semistructured Interview Study. American Journal of Kidney Diseases. 2010 Sep;56(3):439-46.

- **Very similar findings in people with chronic kidney disease, who also have heavy polypharmacy**
- **People assigned implicit priorities to their meds, many regularly skipped ones they considered less important**
- **Medications with noticeable effects tended to be considered more important**

Literacy Level

From MedlinePlus.gov

Rosuvastatin is used together with diet, weight-loss, and exercise to reduce the risk of heart attack and stroke and to decrease the chance that heart surgery will be needed in people who have heart disease or who are at risk of developing heart disease. Rosuvastatin is also used to decrease the amount of cholesterol such as low-density lipoprotein (LDL) cholesterol ('bad cholesterol') and triglycerides in the blood and to increase the amount of high-density lipoprotein (HDL) cholesterol ('good cholesterol') in the blood. Rosuvastatin may also be used to decrease the amount of cholesterol and other fatty substances in the blood in children and teenagers 10 to 17 years of age who have familial heterozygous hypercholesterolemia (an inherited condition in which cholesterol cannot be removed from the body normally). Rosuvastatin is in a class of medications called HMG-CoA reductase inhibitors (statins). It works by slowing the production of cholesterol in the body to decrease the amount of cholesterol that may build up on the walls of the arteries and block blood flow to the heart, brain, and other parts of the body.
Accumulation of cholesterol and fats along the walls of your arteries (a process known as atherosclerosis) decreases blood flow and, therefore, the oxygen supply to your heart, brain, and other parts of your body. Lowering your blood level of cholesterol and fats with rosuvastatin has been shown to prevent heart disease, angina (chest pain), strokes, and heart attacks.

Literacy level = Grade 16 (i.e. college graduate)

“Cultural competence” and culturally specific health beliefs?

- Those strange, exotic people don’t believe in “Western” medicine
- Practitioner needs to know about evil eye/shamanism/rootwork/herbs/ “folk” diseases/voodoo/Chinese medicine/Ayurveda/ . . .
- “My heart hurts”

Okaaaay . . .

- By far the most common non-scientific (“alternative”) health care practice in the U.S. is Christian prayer.
- Healing crystals, GNC, naturopathy, chiropracty, homeopathy, chicken soup . . .
- Throughout the world, scientific (not “western”) medicine has cultural authority – though often alongside other practices
- Non-scientific practices are usually incidental to clinical practice

The real challenges of cross-cultural communication

- **Nearly All** medical encounters are cross-cultural in a meaningful sense

The “Voice” of Medicine

- Rational, scientific world view
- Outcomes defined by repeatable, standard measures: longevity, QALYs, DALYs, lab tests – not necessarily meaningful to Pts
- Medical expertise is arcane, inaccessible to most patients
- Medical expertise is principally biological or technical, reductionist, narrowly specialized

The “Voice” of the Lifeworld

- “Health” a complex construct, no agreed-upon (or possible?) definition
- Health and illness interact with social roles and functional requirements
- Social/physical environment powerfully determine health, beyond reach of medicine
- Pt vs Dr goals typically unexamined

“Disease” vs. “Illness”

- “Disease” = the biomedical perspective
  - Mind-body dualism
  - Biological reductionism

Diseases are abstract entities, similar regardless of the social context or the afflicted individual.

- “Illness” = the patient’s experience
  - Psychological
  - Social
  - Cultural

Illnesses are specific to the individual.

Laws MB, Danielewicz M, Rana A, Kogelman L, Wilson IB. Health literacy in HIV treatment: accurate understanding of key biological treatment principles is not required for good ART adherence. AIDS Behav. 2014 October 30.

Disease: The biomedical perspective

- Mind-body dualism
- Biological reductionism
- Abstract entities which are similar regardless of the psychosocial setting or the afflicted individual

Illness: The patient's experience

- Particular to the individual
- Patterned by psychological, social and cultural factors

Biology quiz: Selected Answers

I'm doing great! My T-cells are undetectable!
HIV causes your immune system to attack your own body
Your body gets saturated with the drugs and you need to stop them for a while

Magic Johnson:

- He's cured
- He gets special secret treatments that only rich people get
- He never had HIV in the first place, just look at him

Few respondents had an accurate understanding of the biology of HIV and anti-retroviral treatment, and this was unrelated to education. Other categories of meaning were more salient.

I wouldn't take my meds. I was like, man, no way. If I start taking these meds, then I have to admit it to myself.

Taking pills

- It means I have it
- It makes me angry that somebody gave it to me
- It makes me feel good that I'm taking care of myself
- I want to set a good example for others

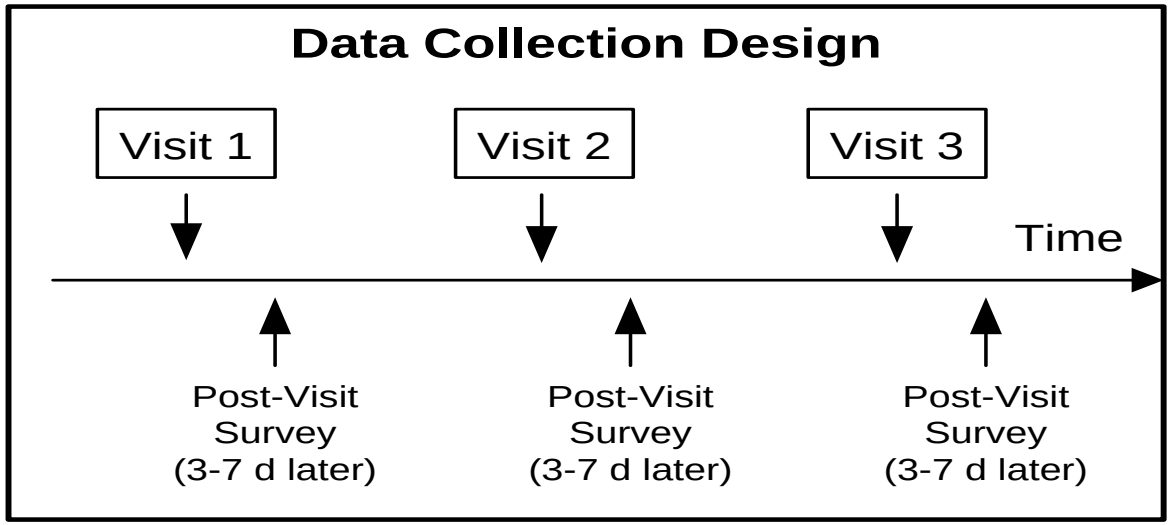
Laws MB, Lee Y, Taubin T, Rogers WS, Wilson IB. Paper under review

Participants:

- Physicians in cardiology and nephrology clinics
- ≈ 10 patients of each physician who are newly referred for heart failure or chronic kidney disease, or have active management issues.

Data:

- Audio recordings of the first visit, and subsequent visits if possible, for each patient, which are transcribed
- Telephone interviews with patient, a few days after each visit



Hypotheses

Patient recall and understanding will be associated with:

These happened too infrequently to be assessed

- "Teach back" method
- Agenda setting
- Provider open questions
- "Wrap up"
- Less provider verbal dominance (i.e., patient talks more, asks more questions)
- Patient formal education
- # of Decisions/recommendations in visit

	Recall Quality: All			
Education	Erroneous or No Recall	Recalled with prompt	Recalled freely and accurately	Total
<12th grade	81 (33%)	73 (20%)	94 (38%)	248
12th grade	62 (15%)	172 (41%)	184 (44%)	418
Some college	42 (11%)	141 (38%)	185 (50%)	368
4 yrs. college	14 (5%)	85 (30%)	186 (65%)	285
Total	199 (15%)	471 (36%)	649 (49%)	1,319

	Medical			Behavioral		
	Beta**	SE	p-value	Beta**	SE	p-value
Resolution count x patient education	0.05	0.04	0.20	0.10	0.04	0.03
Provider/total utterances*	-0.02	0.01	0.02	-0.04	0.01	0.01
Patient education†	0.38	0.61	0.53	-0.80	0.83	0.34
Resolution count/visit	-0.03	0.03	0.42	-0.08	0.04	0.04

* This fraction refers to the ratio of provider utterances to total utterances in the "resolution process."

** Beta can be interpreted as the change in odds ratio of being in a higher category of the dependent variable for each increment of the independent variable

† (1=≥12 years, 0=<12 years)

Summary of Issues

People with limited education and basic skills, and/or less cognitive capacity, may have more difficulty understanding information and instructions and navigating the health care system, but:

- Few people, unless they were biology majors, readily understand the biomedical concepts and thinking physicians use. Clinical communication requires finding the common ground between how physicians think and how patients think, and communicating what the patient wants or needs to know in appropriate terms.
- Accurate understanding and health beliefs may be necessary to self-management and effective physician-patient communication, but they are not sufficient. People make decisions and take action for other reasons.
- Cultural and linguistic competency are essential to successful health care; LEP and culturally specific beliefs or experiences often are conflated with “health literacy” but are a special case.
- There are known methods of enhancing patient understanding and recall, and promoting shared decision making, but they are not generally used.
- Complexity of system: selecting insurance plan, navigating multiple providers.
- High reading level of most available information.
- Pseudo-science and quack healers may be more understandable, accessible and friendly than science-based medicine. (Internet doesn’t necessarily help.)

Possible domains of policy response

School curriculum

Funding for community educational outreach

Medical education and CME

Payment reform – team care with Community Health Workers, navigators, nurse-counselors

Develop and promulgate accessible informational materials

Offer a seal of approval for reliable information

Language and cultural competency standards