

Health Literacy, The Patient Experience, and You

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Overview

- Health literacy (HL) defined, and its implications
- What is known about HL among trauma patients
- HL and the patient experience
- HL – a “universal precautions” approach



"IT CAN HOLD A THOUSAND BOOKS,
WHATEVER "BOOKS" ARE..."

What Are We Talking About When We Talk About Health Literacy?

“Everything was happening so fast and everybody was so busy,” and that is why Mitch Winston, 66 years-old and suffering from atrial fibrillation, did not ask his doctor to clarify the complex and potentially dangerous medication regimen that had been prescribed for him upon leaving the hospital emergency department...

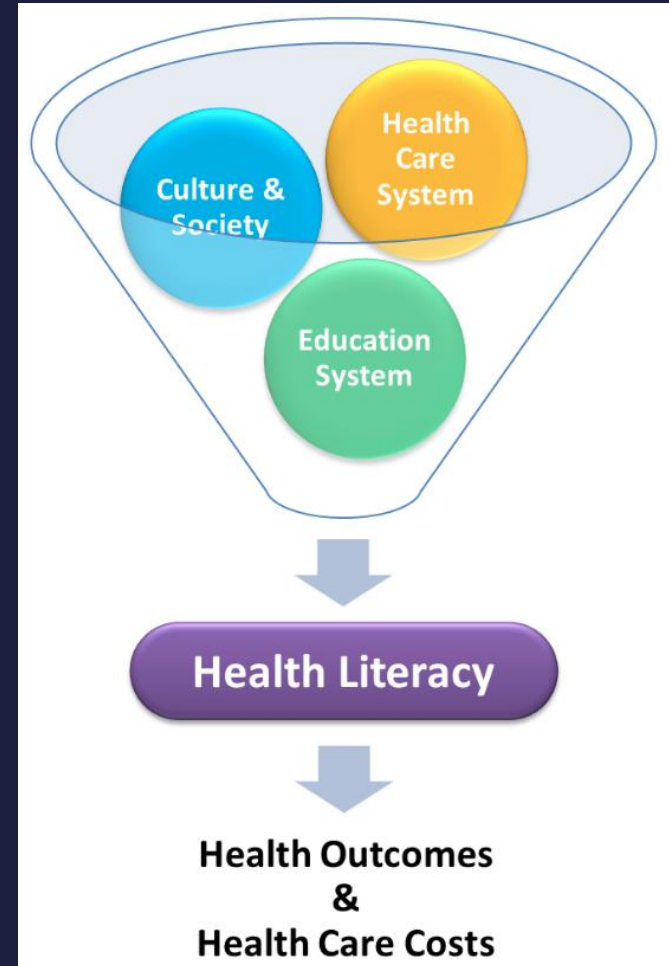
What Are We Talking About When We Talk About Health Literacy?

...When he returned to the emergency department via ambulance, bleeding internally from an overdose of Coumadin, his doctor was surprised to learn that Mitch had not understood the verbal instructions he had received, and that he had ignored the written instructions and orders for follow-up visits that the doctor had provided. In fact, these had never been retrieved from Mitch's wallet.

*"What did the Doctor say?" Improving health literacy to protect patient safety.
The Joint Commission 2007*

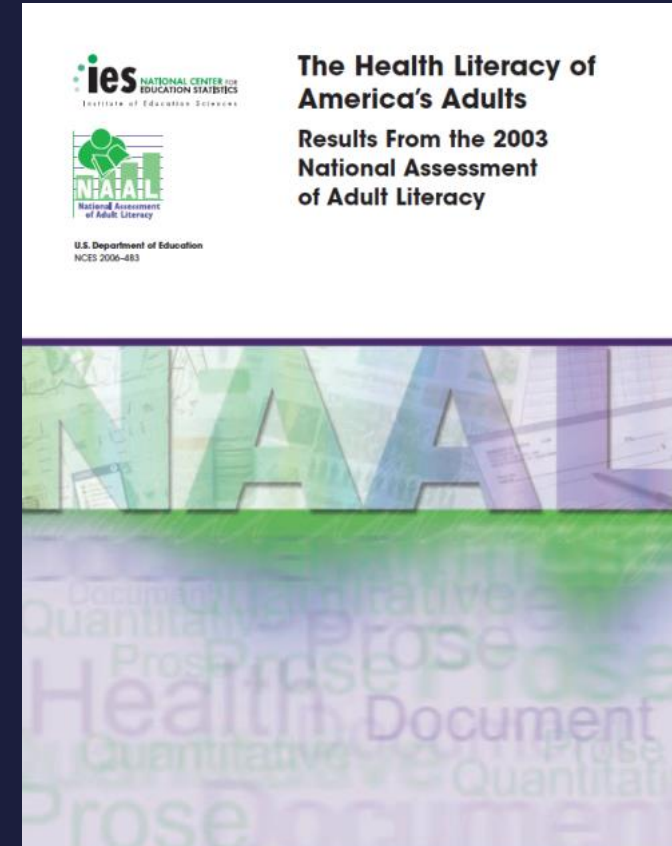
Health Literacy Defined

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



National Assessment of Adult Literacy

- National assessment of health literacy skills of US adults
- Assessed both reading and math skills
- Focused on health-related materials and tasks
- 36% of adults were identified as having serious limitations in health literacy skills



“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,
Former U.S. Surgeon General**

**Mentioned health literacy in
200 of last 260 speeches**

Health Literacy – Impact on Care

“How would you take this medicine?”

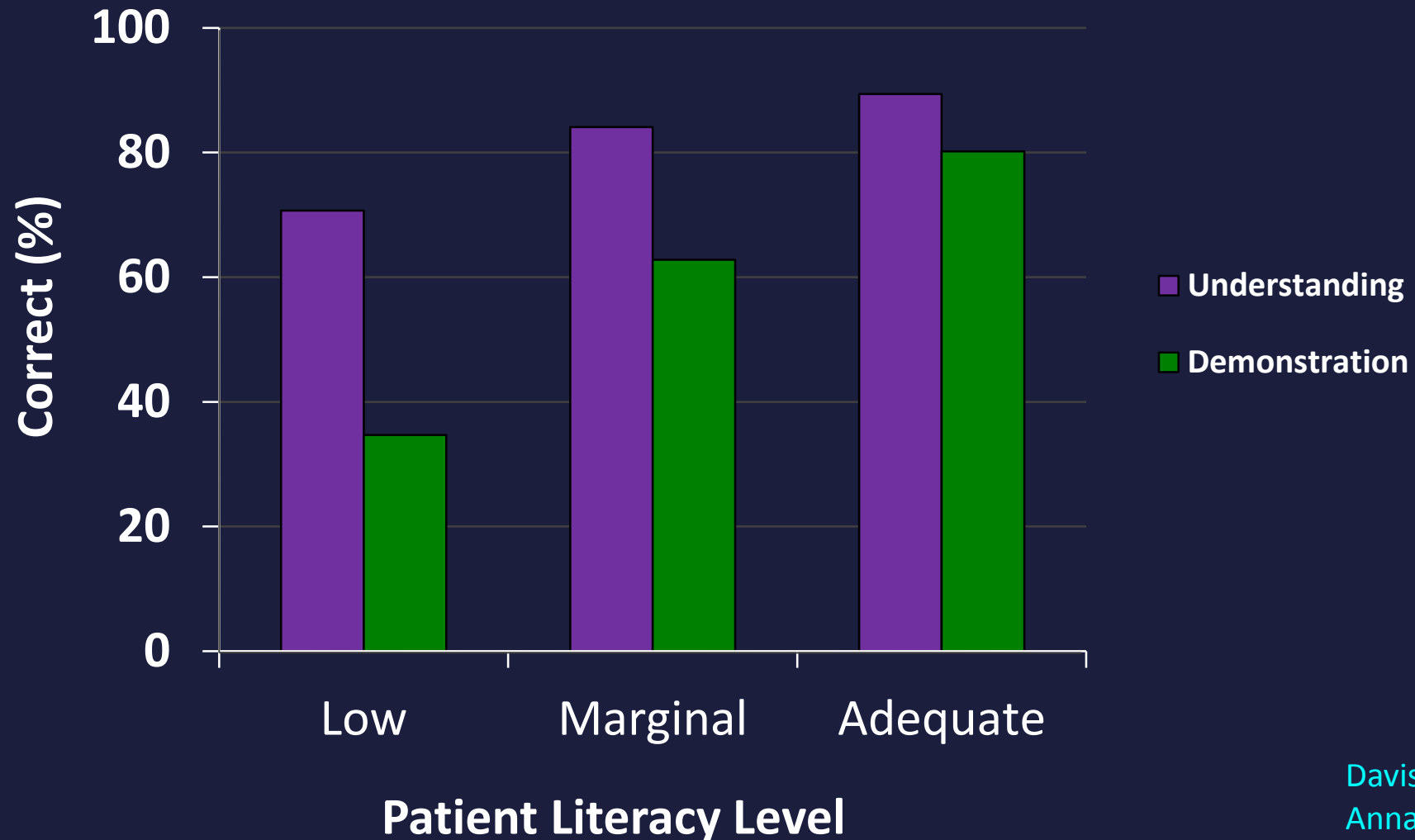
395 primary care patients in 3 States



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

Rates of Correct Understanding vs. Demonstration

“Take Two Tablets by Mouth Twice Daily”



Health Literacy and Outcomes

- Patients with low health literacy:
 - are hospitalized more often and for longer periods of time
 - use emergency departments more frequently
 - manage their diseases less proficiently
- Baker DW, Gazmararian JA, et al, "Functional health literacy and the risk of hospital admission among Medicare managed care enrollees," *American Journal of Public Health*, 2002;92: 1278-1283
- Baker DW, Parker RM, et al, "The health care experience of patients with low literacy," *Archive of Family Medicine*, 1996 5:329-334
- Williams, Mark V., David W. Baker, Eric G. Honig, et al., Inadequate Literacy Is a Barrier to Asthma Knowledge and Self-Care (PDF file), Chest, Vol. 114 (4), American College of Chest Physicians, 1998.
- Schillinger D, Grumbach, K, et al, "Association of health literacy with diabetes outcomes," *JAMA* 2002;288:475-482

The Association of Health Literacy With Preventable Emergency Department Visits: A Cross-sectional Study

Meenakshi P. Balakrishnan, MPH, PhD, Jill Boylston Herndon, PhD, Jingnan Zhang, PhD, Thomas Payton, MD, MBA, Jonathan Shuster, PhD, and Donna L. Carden, MD, MPH

ACADEMIC EMERGENCY MEDICINE • September 2017, Vol. 24, No. 9 • www.aemj.org

	Limited HL	Adequate HL	RR of Being Potentially Preventable
Total Preventable ED Visits	12.1%	7.4%	1.62 (1.09 – 2.41)
Preventable ED Visits Resulting in Hospitalization	24.3%	14.7%	1.65 (1.07 – 2.54)
Preventable ED Visits Resulting in Treat & Release	5.9%	4.7%	1.23 (0.82 – 1.85)

Trauma health literacy: In need of remediation

**Charles P. Shahan, MD, Jordan A. Weinberg, MD, Louis J. Magnotti, MD,
Timothy C. Fabian, MD, and Martin A. Croce, MD, *Memphis, Tennessee***

- Trauma patients were surveyed for knowledge of their injuries, operations, and satisfaction with their care at the first outpatient visit following hospital discharge from a Level 1 trauma center
- 175 surveys, 35 were returned and legible, leaving 20% of surveys for analysis

Please list all of the injuries that you can recall. Be as specific as possible.

☐ I cannot recall any of my injuries

- | | |
|----|-----|
| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

Please list all of the operations (if any) you underwent in the hospital. Be as specific as possible

☐ I had an operation but I cannot remember exactly what was done

- 1.
- 2.
- 3.
- 4.

Please name any doctors (interns, residents, or attendings) who took part in your care.

☐ I do not recall the names of any of my doctors

- | | |
|----|----|
| 1. | 4. |
| 2. | 5. |
| 3. | 6. |

What is your highest level of education completed?

- ☐ Some high school or less
- ☐ High school diploma
- ☐ Some college
- ☐ Completed college
- ☐ Professional degree

Which group best describes your yearly household income?

- ☐ \$0 – 24,999
- ☐ \$25,000 – 49,999
- ☐ \$50,000 – 100,000
- ☐ More than \$100,000

How would you describe your overall understanding of your injuries and operations?

- ☐ I understand very well and can recall them easily
- ☐ I understand somewhat and can recall with some assistance
- ☐ I do not understand well and have trouble remembering some of them
- ☐ I do not understand my injuries or operations at all

How satisfied are you with your understanding of your injuries and operations?

- ☐ I am very satisfied with my understanding of my injuries and operations
- ☐ I am somewhat satisfied but would like to understand a little better
- ☐ I am not satisfied and would like to understand better
- ☐ I am not at all satisfied with my understanding of my injuries and operations

How do you think your understanding of your injuries and operations affected the overall satisfaction of your hospital stay?

- ☐ Positively impacted my overall hospital stay
- ☐ Did not impact my overall hospital stay
- ☐ Negatively affected my overall hospital stay

Figure 1. Survey.

Demographics

Number	35
% Male	75
Age	32

Demographics

Number	35
% Male	75
Age	32
ISS	8
Days to follow up	16

Mechanism of Injury

Motor Vehicle Collision	44%
Gunshot Wound	33%
Stab Wound	11%
Other	12%

Education

Some High School	23%
High School Diploma	39%
Some College	29%
College Degree	6%
Professional Degree	3%

Income

\$0 – \$24,999	71%
\$25,000 – \$49,999	16%
\$50,000 – \$100,000	13%
>\$100,000	0%

Recall

Unable to recall injuries	40%
Unable to recall operations	54%
Unable to name a physician	71%

Satisfaction

At least somewhat satisfied with
injury/operation understanding 91%

Injury understanding had negative
impact on hospital stay satisfaction 4%

Trauma health literacy: In need of remediation

Charles P. Shahan, MD, Jordan A. Weinberg, MD, Louis J. Magnotti, MD,
Timothy C. Fabian, MD, and Martin A. Croce, MD, *Memphis, Tennessee*

- Conclusions:
 - Patient's surveyed had relatively poor ability to name their injuries, their operations, and especially their doctors
 - Patient satisfaction with understanding was relatively high
 - *This study really didn't directly assess health literacy*



Assessments for HL - SAHL

Stem	Key or Distracter		Don't know
1. kidney	__urine	__fever	__don't know
2. occupation	__work	__education	__don't know
3. medication	__instrument	__treatment	__don't know
4. nutrition	__healthy	__soda	__don't know
5. miscarriage	__loss	__marriage	__don't know
6. infection	__plant	__virus	__don't know
7. alcoholism	__addiction	__recreation	__don't know
8. pregnancy	__birth	__childhood	__don't know
9. seizure	__dizzy	__calm	__don't know
10. dose	__sleep	__amount	__don't know
11. hormones	__growth	__harmony	__don't know
12. abnormal	__different	__similar	__don't know
13. directed	__instruction	__decision	__don't know
14. nerves	__bored	__anxiety	__don't know
15. constipation	__blocked	__loose	__don't know
16. diagnosis	__evaluation	__recovery	__don't know
17. hemorrhoids	__veins	__heart	__don't know
18. syphilis	__contraception	__condom	__don't know

Prospective Evaluation of Low Health Literacy and Its Impact on Trauma Patients

Swartz T et al. J Trauma Acute Care Surg 2018

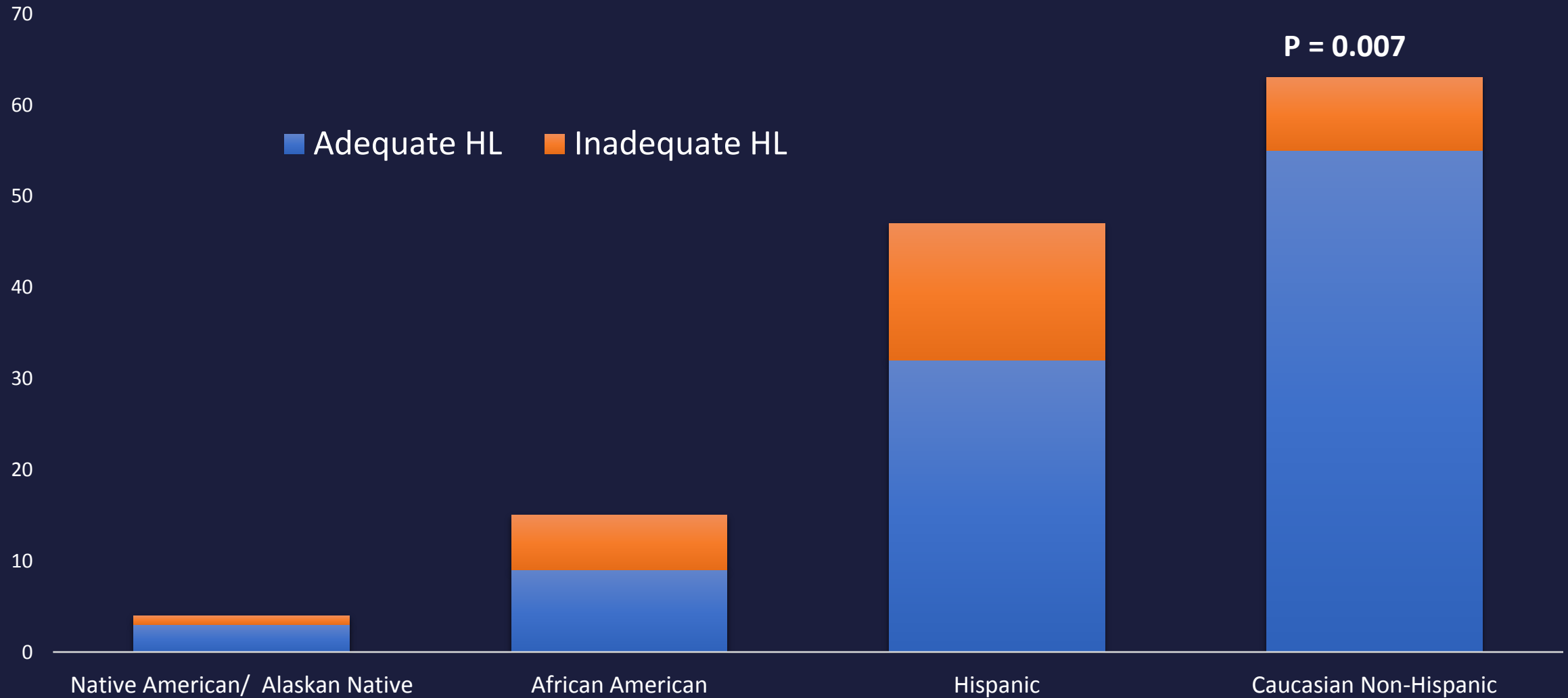
Characteristics	Odds Ratio	95% Confidence Interval	P Value
Low-health literacy			
Clinic follow-up	0.78	0.66 – 0.89	0.03
ED visits	1.25	1.11 – 1.99	0.03
Compliance DC instructions	0.71	0.55 – 0.81	0.01
Complications	1.31	1.22 – 2.42	0.02

Regression analysis for 30-day outcomes, controlling for demographics, injury parameters, mechanism of injury and ED vitals

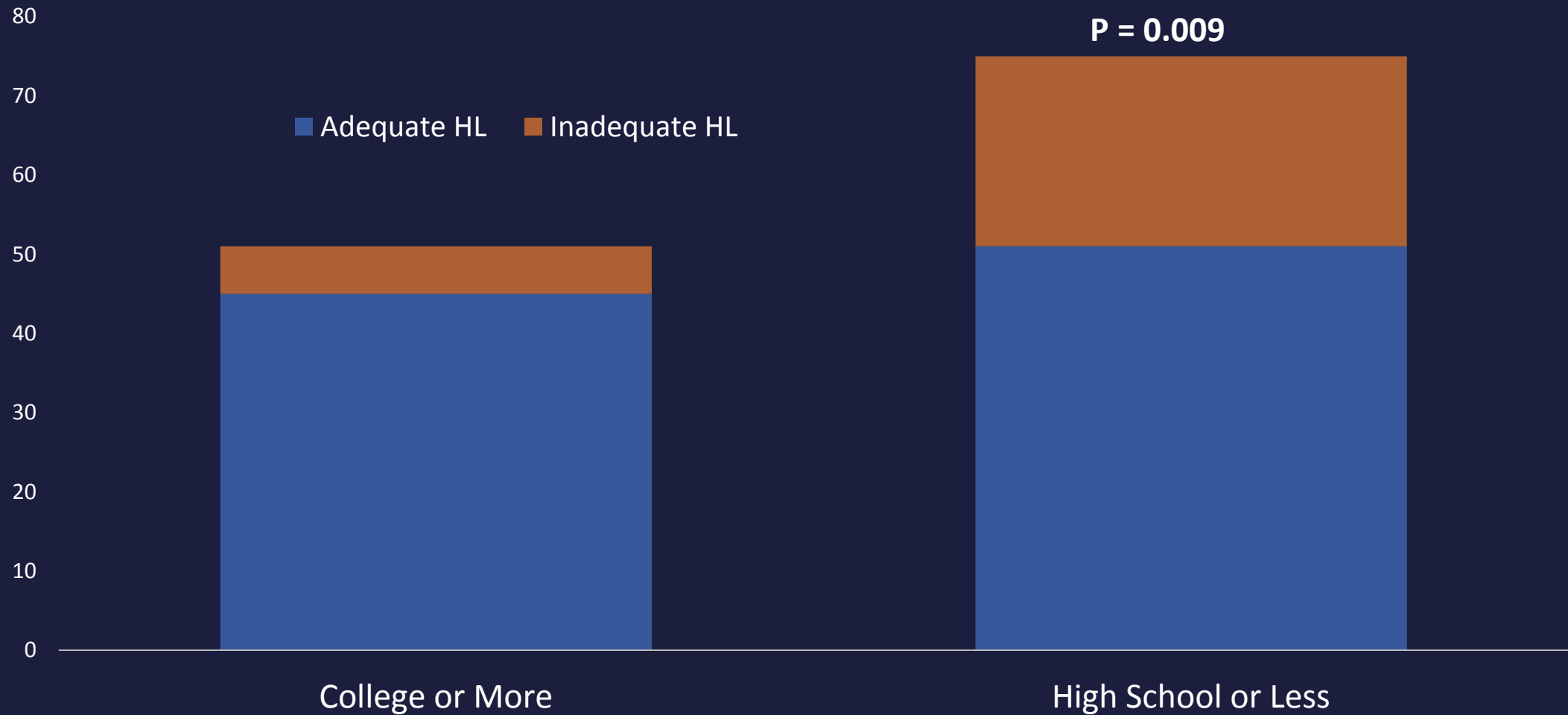
Low Health Literacy: Who is at risk?

- 128 adult trauma patients at SJHMC completed the Short Assessment of Health Literacy (SAHL) during their stay
 - Average patient age was 44
 - 33% female
 - Median ISS 10
- 31 patients (24.2%) had low HL by SAHL result

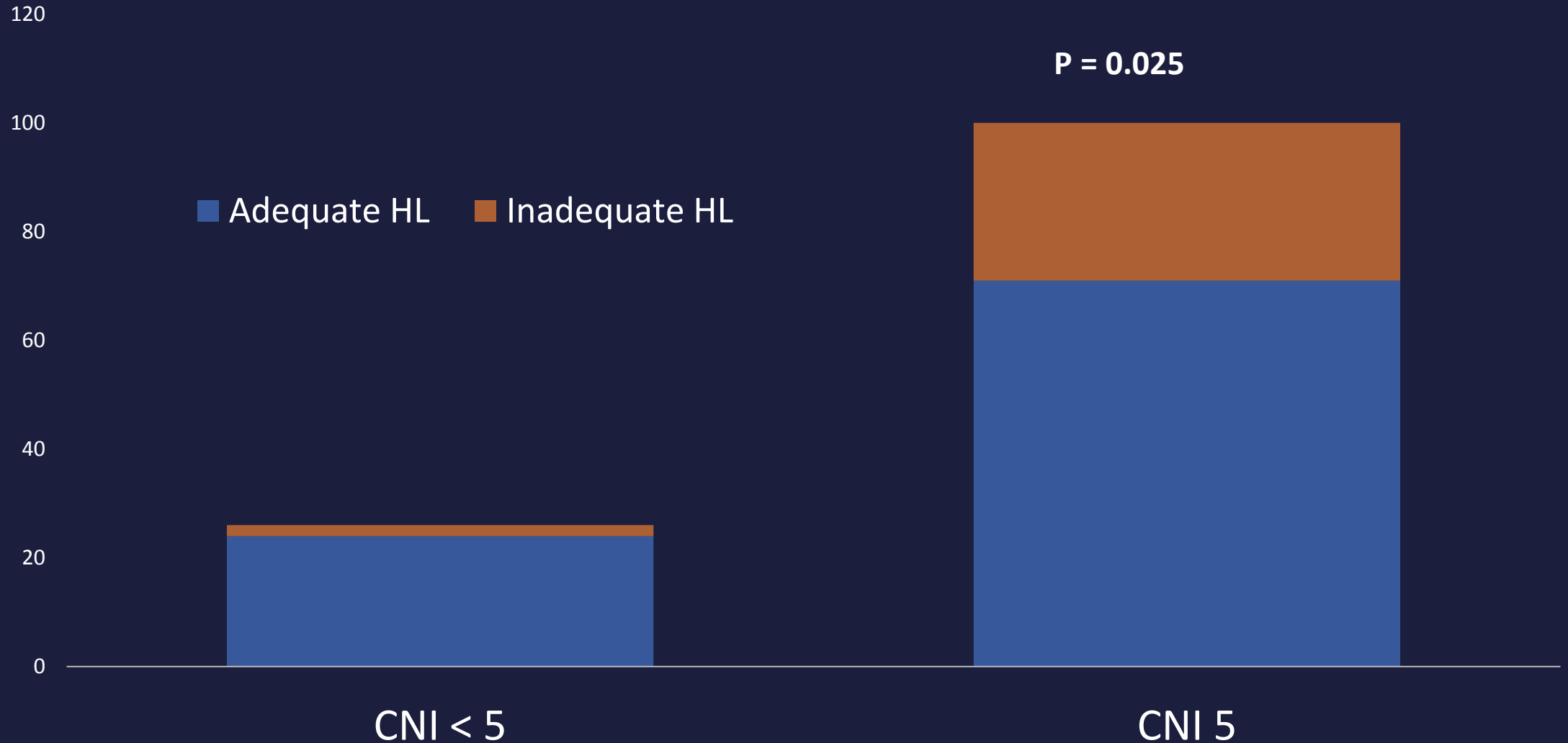
Low Health Literacy: Who is at risk?



Low Health Literacy: Who is at risk?



Low Health Literacy: Who is at risk?



Trauma Patient Health Literacy

- Approximately one quarter of our trauma patients have deficient HL
- Not surprisingly, deficient HL was associated with race/ethnicity, education level, and socioeconomic conditions
- Identifying patients with low HL is relatively easy

Assessments for HL – Newest Vital Sign (NVS)

Nutrition Facts

Serving Size $\frac{1}{2}$ cup
Servings per container 4

Amount per serving

Calories	250	Fat Cal	120
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%DV

Total Fat	13g	20%
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Sat Fat	9g	40%
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Cholesterol	28mg	12%
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Sodium	55mg	2%
--------	------	----

Total Carbohydrate	30g	12%
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Dietary Fiber	2g
---------------	----

Sugars	23g
--------	-----

Protein	4g	8%
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*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?

Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?

Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl."

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer: 33 is the only correct answer

4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer: 10% is the only correct answer

READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?

Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?

Answer: Because it has peanut oil.

ANSWER CORRECT?

yes	no
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Interpretation

Number of correct answers:

Score of 0-1 suggests high likelihood (50% or more) of limited literacy

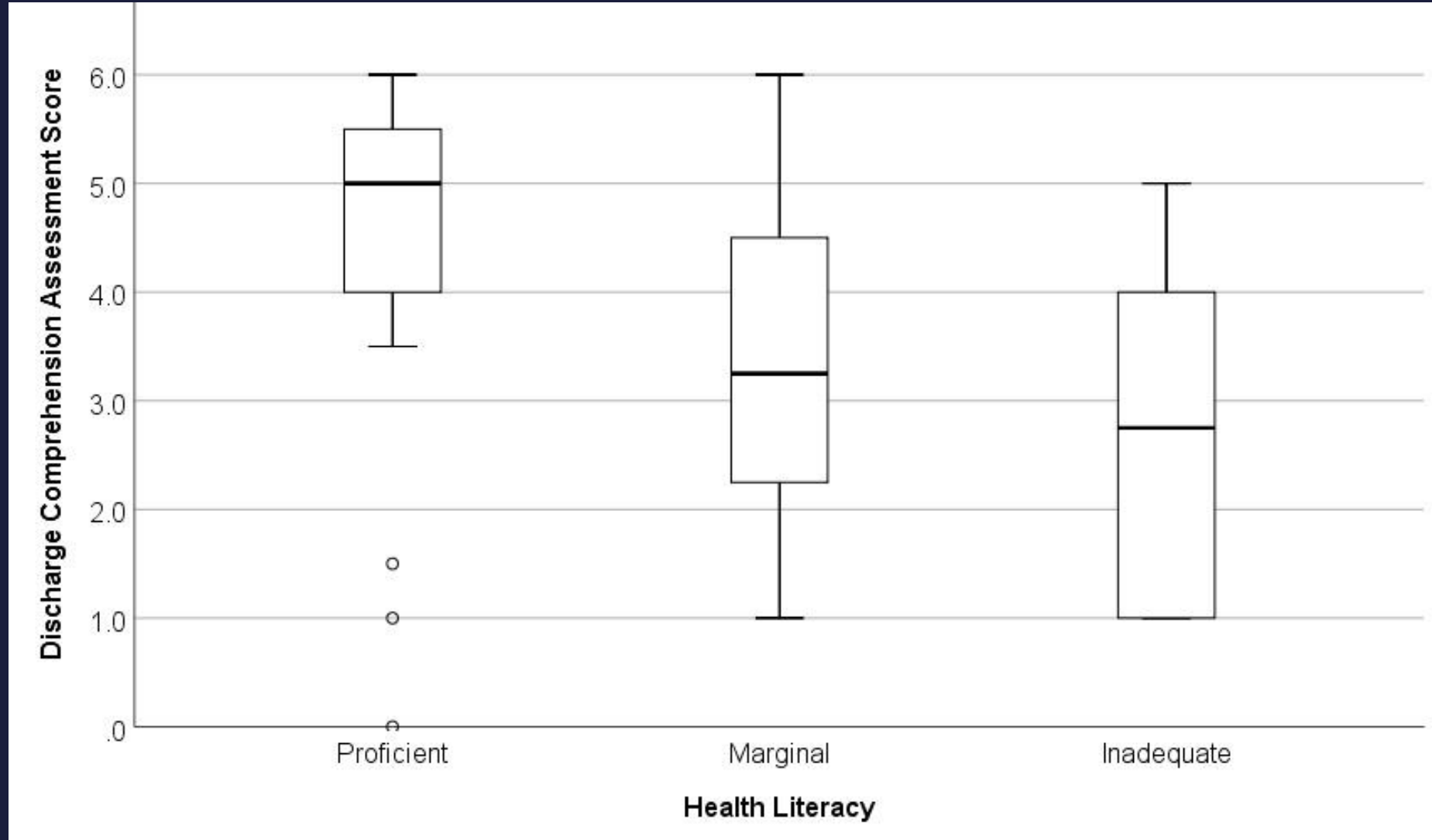
Score of 2-3 indicates the possibility of limited literacy.

Score of 4-6 almost always indicates adequate literacy.

Assessments for HL – Newest Vital Sign (NVS)

Item	Content Area	Question
1	Medications	Which new medications were prescribed at discharge?
2	Medications	What is the purpose of each medication you were given?
3	Medications	Were you given any warnings about the new medications prescribed to you?
4	Instructions	Were you told to schedule a follow-up appointment after discharge?
5	Instructions	When is the follow-up date scheduled for? Or, for when did they tell you to schedule it?
6	Instructions	What were you told about returning to the hospital in case of any specific issues?
7	Wound Care	Were you instructed to maintain a specific environment for your wound site? (i.e., dressing, ointment, etc.)
8	Diet	Were you given a specific diet to follow after discharge?
9	Exercise	Were you told to avoid weight-bearing activities?
10	Exercise	Were you told not to lift objects above a specific weight?
11	Special Care	Were you given any specific instructions for special care? (i.e., ostomy tube, catheter, etc.)
12	Special Care	Were you told to give up a specific habit? (i.e., smoking, drinking, working, etc.)

Assessments for HL – Newest Vital Sign (NVS)



Trauma Patient Health Literacy

- Approximately one quarter of our trauma patients have deficient HL
- Not surprisingly, deficient HL was associated with race/ethnicity, education level, and socioeconomic conditions
- Identifying patients with low HL is relatively easy
- Lower HL is associated with poorer comprehension of discharge instructions

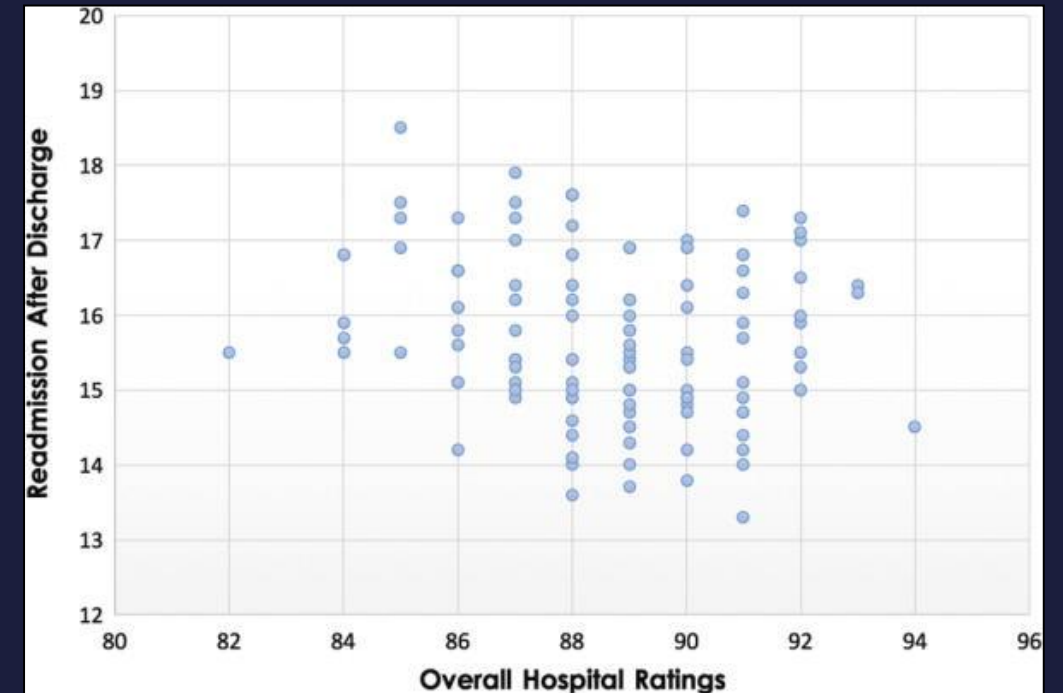
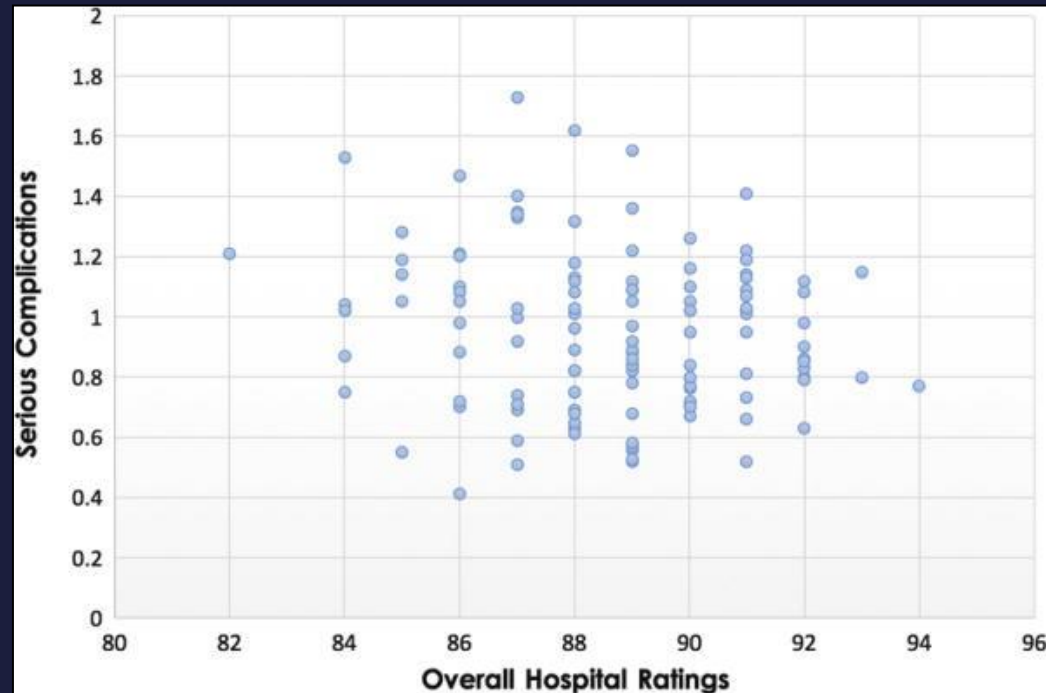
Patient Experience – A Pillar of Healthcare Quality?

- Healthcare Quality
 - Clinical Effectiveness
 - Patient Safety
 - Patient Experience



American College of Surgeons Level I trauma centers outcomes do not correlate with patients' perception of hospital experience

Bellal Joseph, MD, Asad Azim, MD, Terence O'Keeffe, MD, Kareem Ibraheem, MD, Narong Kulvatunyou, MD, Andrew Tang, MD, Gary Vercruysse, MD, Randall Friese, MD, Rifat Latifi, MD, and Peter Rhee, MD, MPH, Tucson, Arizona



A systematic review of evidence on the links between patient experience and clinical safety and effectiveness

Cathal Doyle,¹ Laura Lennox,^{1,2} Derek Bell^{1,2}

2013

Table 3 Associations categorised by type of outcome

	Objective' health outcomes	Self-reported health and wellbeing	Adherence to treatment (including medication)	Preventive care	Healthcare resource use	Adverse events	Technical quality of care	All categories
No of positive associations found	29	61	152	24	31	7	8	312
'No associations'	11	36	7	2	6	0	4	66

Health Literacy and the Patient Experience

- Perception of the quality of physician-patient communication may be influenced by patient level of health literacy (HL)
- With respect to hospitalized trauma patients, the influence of HL on perception of physician-patient communication is relatively unknown
- We sought to determine the baseline level of satisfaction with physician-patient communication on our trauma service and to evaluate the effect of HL on satisfaction ratings

Dameworth et al. J Trauma Acute Care Surg 2018

Methods

- Hospitalized trauma patients at an SJHMC were asked to participate in survey prior to discharge:
 - Short Assessment of Health Literacy (SAHL)
 - Validated test of level of health literacy – HL-adequate vs. HL-deficient
 - Short Form-Interpersonal processes of Care (SF-IPC)
 - Validated satisfaction survey of physician-patient communication with results stratified to six communication domains scored from 1 to 5
- Rates of “top box” (5/5) scores for each SF-IPC domain were compared between HL-deficiency and HL-adequate patient groups

INTERPERSONAL PROCESSES OF CARE SURVEY: SHORT FORM

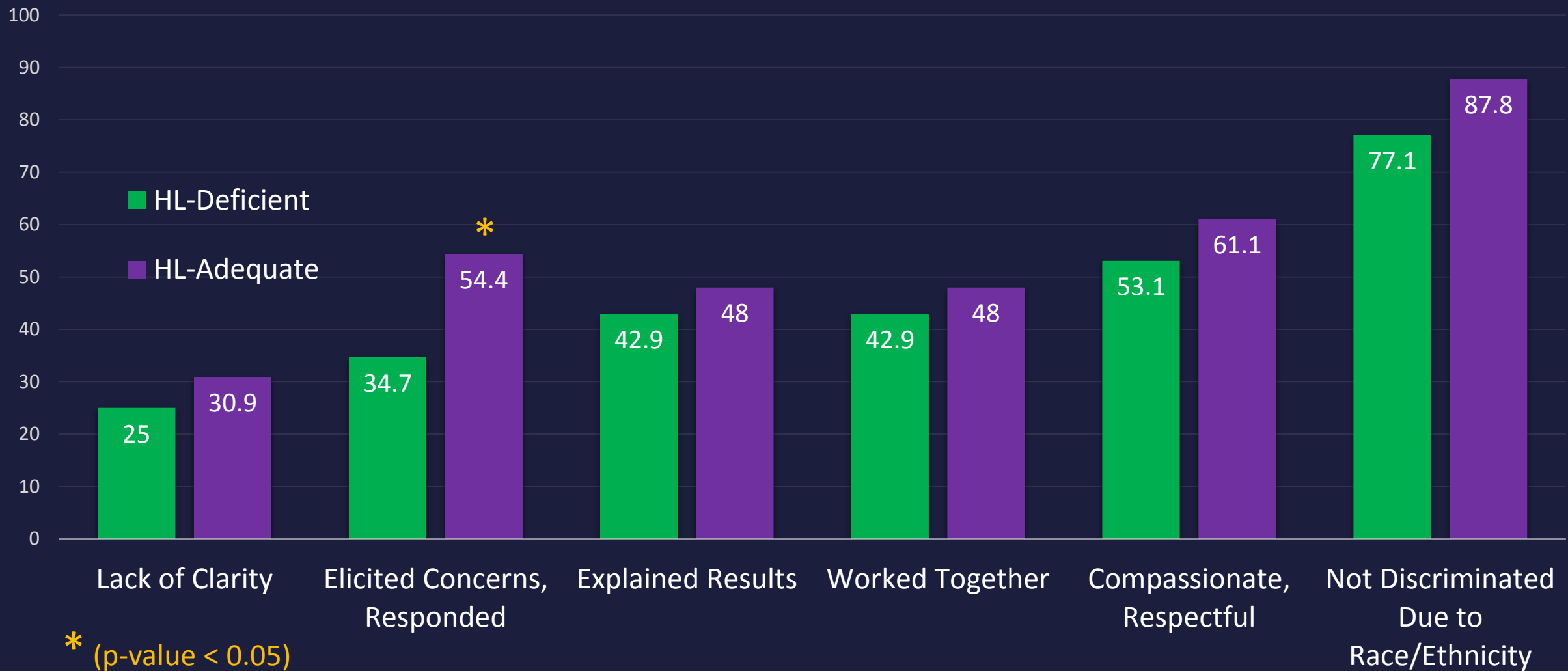
	Never	Rarely	Sometimes	Usually	Always
1. How often did doctors speak too fast?	1	2	3	4	5
2. How often did doctors use words that were hard to understand?	1	2	3	4	5
6. How often did doctors really find out what your concerns were?	1	2	3	4	5
7. How often did doctors let you say what you thought was important?	1	2	3	4	5
8. How often did your doctors take your health concerns very seriously?	1	2	3	4	5
9. How often did doctors explain your test results such as blood tests, x-rays, or cancer screening tests?	1	2	3	4	5
10. How often did doctors clearly explain the results of your physical exam?	1	2	3	4	5
15. How often did you and your doctors work out a treatment plan together?	1	2	3	4	5
16. If there were treatment choices, how often did doctors ask if you would like to help decide your treatment?	1	2	3	4	5
19. How often were doctors concerned about your feelings?	1	2	3	4	5
20. How often did doctors really respect you as a person?	1	2	3	4	5
21. How often did doctors treat you as an equal?	1	2	3	4	5
24. How often did doctors pay less attention to you because of your race or ethnicity?	1	2	3	4	5
25. How often did you feel discriminated against by doctors because of your race or ethnicity?	1	2	3	4	5

* Question numbers are from the original 29-question survey (IPC-29)

† List of questions modified from Interpersonal Processes of Care Survey Short Form (IPC-18) © 2006, University of California San Francisco
<https://dgim.ucsf.edu/cadc/mm/ipcare.html>

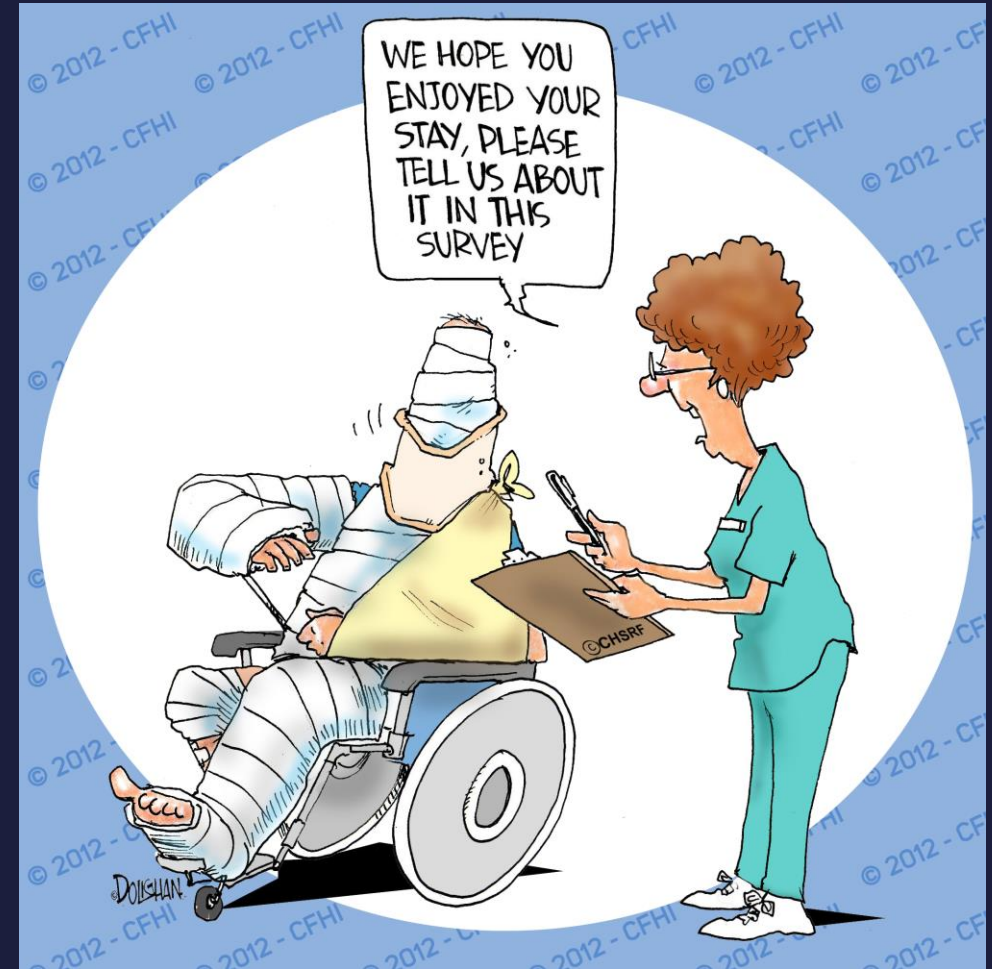
	HL-Deficient (n = 49)	HL-Adequate (n = 150)	p-value
Mean Age	40.8	42.5	0.567
Gender: Male	75.5%	64.7%	0.16
Race/Ethnicity: Non-Hispanic White	32.7%	51.3%	0.023
Self-reported familiarity with medical terminology	55.8%	78.2%	0.004
Education level: More than high-school education	17.4%	49.3%	<0.0001

IPC Survey “Top-Box” Scores by Domain



Summary

- HL-deficient patients tended to rate their physician-patient interactions lower than HL-adequate patients and significantly less likely to rate that their concerns were always elicited by their physicians
- Patients were generally unlikely to rate physician-patient encounters in the “top-box” irrespective of level of HL



What to do next?

- Screen patients for deficiencies in health literacy
 - Tailor communications, both oral and written to HL-deficient patients

OR

- Assume deficient HL in all patients
 - The “universal precautions” approach



The Universal Precautions Approach to HL

MEDICINE IS A FOREIGN LANGUAGE

“To be fluent in a second language, you need a working vocabulary of about 5,000 words. To be fluent in Medicine, you need double that. The whole purpose of med school is to learn to be fluent in Medicine.”

Some guy I went to med school with, 1995

The Universal Precautions Approach to HL

PATIENTS (i.e. HUMANS) ARE WIRED TO FEIGN UNDERSTANDING YOU

Intimidation

Shame

When Toni Cordell – a well-spoken working woman and mother – consented to her hysterectomy, everything went well. Toni had a good outcome from her surgery.

The only problem was that Toni did not know she was having a hysterectomy until after it had occurred.

“What did the Doctor say?” Improving health literacy to protect patient safety.
The Joint Commission 2007

The Universal Precautions Approach to HL

PATIENTS (i.e. HUMANS) ARE WIRED TO FEIGN UNDERSTANDING YOU

Intimidation

Shame

Take the case of Mr. Garcia, who needed to have his staples removed. When a resident entered his room, he asked the man in bed if he was Mr. Garcia. The man smiled and agreeably nodded his head. He then had his staples removed...prematurely. He was not Mr. Garcia.

“What did the Doctor say?” Improving health literacy to protect patient safety.
The Joint Commission 2007

The Universal Precautions Approach to HL

- Recommendations from the AMA for physician-patient communication:
 1. Slow down
 2. Use plain, non-medical language
 3. Show or draw pictures
 4. Limit the amount of information provided – and repeat it
 5. Use the “teach back” technique
 6. Create a shame-free environment: encourage questions

The Universal Precautions Approach to HL

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The Role of Inadequate Health Literacy Skills in Colorectal Cancer Screening

Terry C. Davis, Ph.D.,¹ Nancy C. Dolan, M.D.,²
M. Rosario Ferreira, M.D., M.P.P.,³ Cecilia Tomori, B.A.,²
Kristen W. Green, M.A.,¹ Alison M. Sipler, B.A.,² and
Charles L. Bennett, M.D., Ph.D.^{2,4}

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³Robert Wood Johnson Clinical Scholars Program, University of Chicago,
Chicago, Illinois

⁴VA Chicago Health Care System—Lakeside Division, Chicago, Illinois

Cancer Investigation, 19(2), 193–200 (2001)

Focus groups of VA patients and physicians in Chicago area

- Patients did not know cancer-related terms, such as “polyp,” “tumor,” “growth,” or “lesion.”
- Even after the concept of looking for hidden cancer or precancerous lesions was described several times, some focus group members continued to ask what symptoms they should look for and never understood the concept of screening to detect early cancer, hidden cancer, or premalignant lesions
- None of the patient participants knew what the colon or bowel was or where it was located

Examples of Plain Language

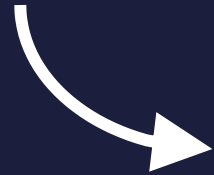
	Plain Language
▪ Annually	Yearly or every year
▪ Arthritis	Pain in joints
▪ Cardiovascular	Having to do with the heart
▪ Dermatologist	Skin doctor
▪ Diabetes	Elevated sugar in the blood
▪ Hypertension	High blood pressure

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Teach-back

Explain



Assess



Clarify



Understanding



Confirm patient understanding

“Tell me what you’ve understood.”

“I want to make sure I explained your medicine clearly. Can you tell me how you will take your medicine?”

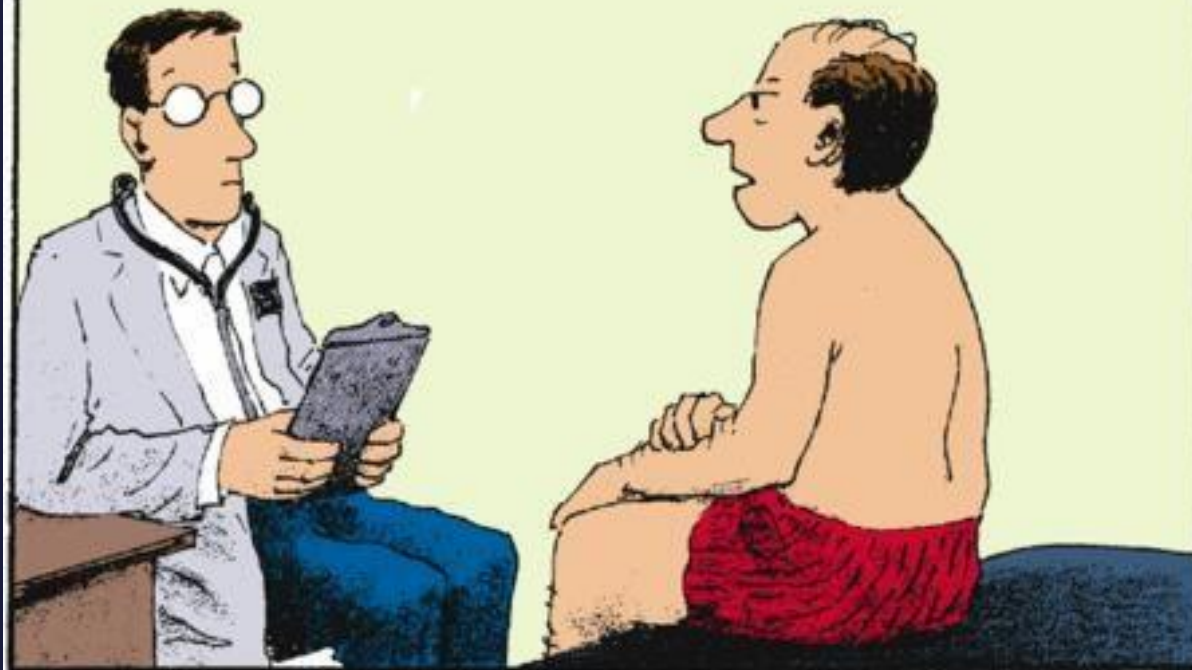


Wrap-up

- Approximately one quarter of our trauma patients have deficient health literacy
- Deficient health literacy is associated with increased ED utilization, post-discharge complications, poorer comprehension of DC instructions, and poorer perception of physician-patient communication
- A universal precautions approach to health literacy makes sense and is encouraged
 - Speak slowly, plainly, and confirm that your patients understand you

HP Bliss

www.harrybliss.com



"Doc, enough with the 'English' — just give it to me in plain academic medical terminology!"