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04. Health literacy and health communication in community engaged research

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Health Literacy and Health Communication in Community Engaged Research

> Russell Rothman MD MPP September 26, 2011

Associate Professor, Internal Medicine & Pediatrics Director, Center for Health Services Research Chief, Internal Medicine & Pediatrics Co-Director, Community Engaged Research



Outline of Talk

- What is health literacy and numeracy?
- Scope of problem
 - Examples in research, nutrition, diabetes, pediatrics
- How to identify low literacy
- What can you do to address literacy?
- Interventions for low literacy and numeracy
- Conclusions

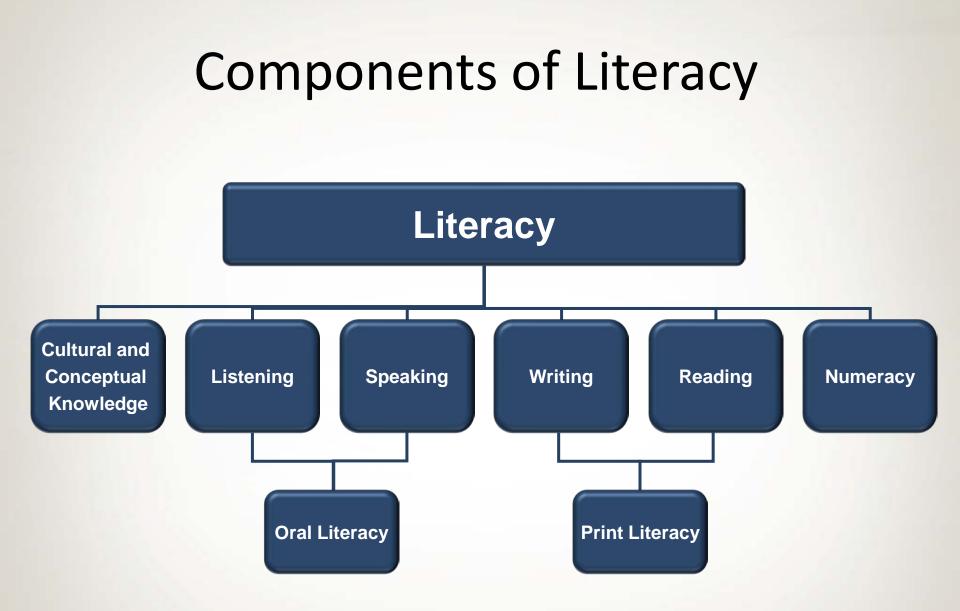


Concern about Literacy and Numeracy Skills



What is Literacy/ Health Literacy?

- Literacy: "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 ones knowledge and potential"
- Health literacy: "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"

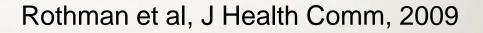


IOM, Health Literacy, 2004



Numeracy

- A component of overall literacy
- "The ability to understand and use numbers and math skills in daily life"
- Calculations, deduction/logic, interpretation of graphs/labels, time, probability, etc.





Numeracy vs Literacy

Highly correlated with literacy, but not perfect



Who has poor literacy?

- NALS (1992) and NAAL (2003)
 - 40-44 million Americas are functionally illiterate
 - 50 million have marginal literacy skills
- Average American reads at 8th-9th grade level
- Low literacy more common among:
 - Immigrants
 - AA, Hispanic, Asian (up to 50%)
 - Elderly (up to 66%)



Who has poor numeracy?

- NALS (1992) and NAAL (2003)
 - 25% could not perform rudimentary skills
 - 32% had only marginal numeracy skills
 - could perform simple one-step arithmetic problems if the numbers were explicitly stated to them
 - could not perform multi-step arithmetic, or determine what math skills were needed when reading a problem.
 - Could not interpret a bus schedule



Why is literacy important in health care and research?

- Patients with low literacy have:
 - Trouble reading prescriptions, following medical instructions
 - Trouble understanding educational materials
 - Trouble interpreting and applying numbers to health situations
 - Trouble consenting to research or procedures
 - Difficulty answering survey items or other measures
 - Difficulty following research protocols



Why is numeracy important in health care?

- Patients with low numeracy may have trouble:
 - Understanding dosages of medications
 - Understanding the timing of when to take medications or have them refilled
 - Interpreting nutritional information
 - Understanding volume status
 - Interpreting blood sugars, adjusting insulin
 - Understanding risks and probability



Impact of Literacy in Health Care and Research

- Less likely to obtain tests or follow-up
- Lower knowledge of their disease
- Lower quality of life and satisfaction measures
- Increased risk for hospitalization
- Poorer clinical outcomes
- Poorer understanding of consent process
- Difficulties with measures and protocol adherence

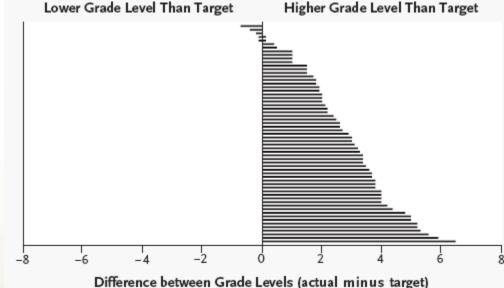


What is it really like for patients?



Health Literacy and Patient Consent Forms

- Reviewed 114 US Medical Schools' IRB text for consent forms
- Average Readability was 10.6th grade level
- Of 61 sites that set targets (5th to 10th grade),
 57 exceeded target: Lower Grade Level Than Target Higher Grade Level Than



•Paasche-Orlow, NEJM, 2003

Examples of Consent Text

ability vel	Voluntary Participation	10th Grade†	"Your participatic study is volun are free to wit
n Grade†	"You don't have to be in this research study. You can agree to be in the study		time. Participa withdrawal wi any rights to v are entitled."
	now and change your mind later. Your decision will not affect your regular care. Your doctor's attitude to- ward you will not change."	12th Grade¶	"Your participation in this study is strictly voluntary. You have the right to choose not to participate or to withdraw your partic ipation at any point in this study without prejudice to your future health care or other services to which you are otherwise entitled."
Grade†	"Taking part in this study is your choice. If you decide not to take part, this will not harm your relations with your doctors or with the University."		
Grade†	"Participation in this study is entirely voluntary. You have the right to leave the study at any time. Leaving the study will not result in any penalty or loss of ben- efits to which you are entitled."	College¶	"You voluntarily co participate in t search investig may refuse to in this investig withdraw your and discontinu tion in this stu penalty and wi fecting your fu or your ability
RSITY			alternative me ment at the U

Health Communication and Consent Process

- Often confirmation of patient understanding of consent is not adequately performed
- Consent process more challenging in patients with limited English proficiency
- Subjects often sign consent quickly without complete understanding of risks
- Study of online consent form for genetic study demonstrated that:
 - median time to consent was 53 seconds.
 - 23% of participants consented within 10 seconds,
 - 93% of participants consented in less than the minimum predicted reading time.

VANDERBILT WUNIVERSITY MEDICAL CENTER K Desche, Annals of Int Med, 2011

Outcomes Associated with Literacy

Health Outcomes/Health Services

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



Behaviors Only

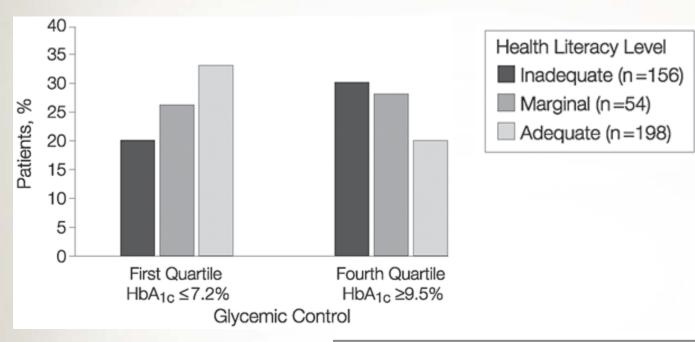
- Substance abuse
- Breastfeeding
- Behavioral problems
- Adherence to medication
- Smoking

Knowledge Only

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

DeWalt, JGIM 2004

Literacy and Diabetes Outcomes



Complication	Study Subjects With Complication, No.	Odds Ratio (95% Confidence Interval)	<i>P</i> Value
Retinopathy	111	2.33 (1.19-4.57)	.01
Nephropathy	62	1.71 (0.75-3.90)	.20
Lower extremity amputation	27	2.48 (0.74-8.34)	.14
Cerebrovascular disease	46	2.71 (1.06-6.97)	.04
Ischemic heart disease	93	1.73 (0.83-3.60)	.15

*Adjusted for age, sex, race, education, insurance, language, social support, depression, treatment regimen, years with diabetes, and diabetes education, and accounting for clustering of patients within physicians. Hypertension was included in the models for retinopathy and nephropathy; hypertension and smoking were included for all others.

Schillinger, JAMA, 2002

Numeracy and Food Labels

Servings Per Container 4	A. Serving Size Information
Amount Per Serving	B. Caloric Information
Calories 90 Calories from Fat 30	C. Percent Daily Value
% Daily Value* Total Fat 3g 5%	C. Percent Daily value
Saturated Fat 0g 0%	
Cholesterol Omg 0%	
Sodium 300mg 13%	
Total Carbohydrate 13g 4%	
Dietary Fiber 3g 12%	
Sugars 3g	
Protein 3g	D. Nutrient Information
Vitamin A 80% • Vitamin C 60%	
Calcium 4% Iron 4%	
Percent Daily Values are based on a 2,000	
calorie diet. Your daily values may be higher or lower depending on your calorie needs:	E. Footnote of Daily Values
Calories: 2,000 2,500	
Total Fat Less than 65g 80g Sat Fat Less than 20g 25g	
Cholesterol Less than 300mg 300mg	
Sodium Less than 2,400mg 2,400mg	
Total Carbohydrate 300g 375g Dietary Fiber 25g 30g	

Demographics

Variable (n=200)	Avg (SD) or Percent
Age	43 (15)
Female	72%
African American	25%
Family Income < \$20,000	25%
Private Insurance	75%
HS education or less	33%
Chronic Illness requiring dietary restriction	41%
BMI (n=151)	30 (7)
Reads Food Labels	89%

Literacy, Numeracy, Food Labels

Variable (n=200)	Percent
Literacy (REALM) <= 8 th Grade	23%
Numeracy (WRAT) <= 8 th Grade	63%
Food Label Score (Range 30% - 100%)	69% (19%)
Internal Reliability (KR 20)	0.87



Sample Questions and Results

- You drink this whole bottle of soda. How many grams of total carbohydrates does this contain?
- Correct Response: 67.5 grams
- Only 32% answered correctly.



•How many grams of dietary fiber are in 5 candies?

Correct Response: 1 gram

Percent Correct 66 %



Nutrition Score by Characteristics

Variable (n=200)	Mean Nutrition Score (SD)	p value
Age < 65 ≥ 65 yrs	70 (21) 59 (19)	0.04
Gender Female Male	67 (21) 74 (20)	0.04
Race White Black Other	74 (19) 57 (18) 77 (18)	<0.0001
Private Insurance Yes No	73 (20) 59 (19)	<0.0001
Chronic Illness* Yes No	65 (20) 72 (20)	0.04
BMI < 30 ≥ 30	73 (21) 66 (20)	0.04

Nutrition Score Correlations

- Higher performance on the food label survey was significantly correlated with:
 - Higher education (r=0.44)
 - Higher income (r=0.56)
 - Higher literacy (r=0.52)
 - Higher numeracy (r=0.67)



Conclusions

- Patient comprehension of food labels was fair.
- Comprehension was worse when patient needed to apply serving sizes, or perform multi-step math.
- Comprehension was worse for patients who were obese or had chronic illness
- Comprehension was highly correlated with math and literacy skills



Numeracy and Diabetes



Diabetes and Numeracy Study

- Cross sectional survey of 398 patients
- Mean score on Diabetes Numeracy Test was 61% (SD 25%)
- Trouble Spots
 - Interpreting serving sizes
 - Fractions or decimals
 - Applying multi-step regimens (ex. sliding scale and carb-ratios)
 - Applying titration instructions

VANDERBILT WUNIVERSITY MEDICAL CENTER •Huizinga et al, BMC Health Services Res, 2008 •Cavanaugh et al, Annals of Internal Medicine, 2008

Serving Size

 If you ate the entire bag of chips, how many total grams of carbohydrate would you eat?

Correct Response: 63 gms Correct: 44%



Monitoring

 Your target blood sugar is between 60 and 120. Please circle the values below that are in the target range (circle all that apply):

55

145

118

Correct Response: Circle 118 only Percent Correct: 74%



Insulin Correction Scale (I)

 You are told to follow the sliding scale shown here. The sliding scale indicates the amount of insulin you take based upon your blood sugar levels:

If Blood sugar is:	Units of Insulin
130-180	0
181-230	1
231-280	2
281-330	3
331-380	4

Percent Correct: 85%



Insulin Correction Scale (II)

After seeing the Doctor, you are given the following instruction to lower a high blood sugar level before a meal:

" Starting with a blood sugar of 120, take 1 unit of Humalog insulin for each 50 points of blood sugar."

How much insulin should you take for a blood sugar of 375?

43. ANSWER ______ units

Percent Correct: 37% (accept 5-6units)



DNT and other measures

- Higher DNT scores are sig. correlated with higher:
 - education (r=0.51)
 - literacy (r=0.50)
 - math skills (r=0.64)
 - diabetes knowledge (r=0.78)
 - Frequency of glucose monitoring (r=0.21)

and lower:

– A1C (r= -0.08, p =0.11)

In multivariate analysis, each 10 point increase in DNT score was correlated with a 0.1 point decrease in A1C (p<0.05).

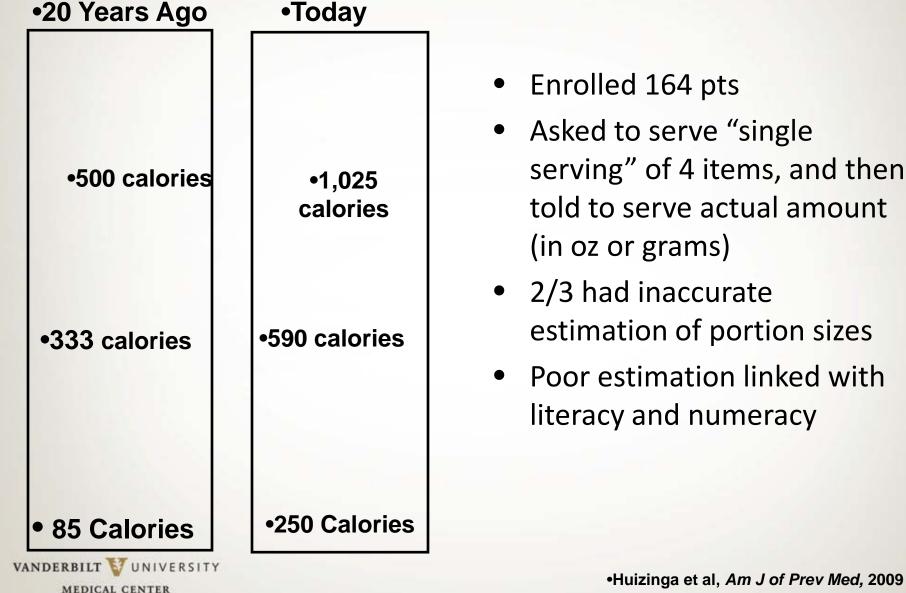


Conclusions

- Performance on DNT was fair/poor
- Disconnect between what is taught and what patients can do.
- Performance on DNT was correlated with literacy and math skills.
- Performance on DNT was also correlated with A1C, when adjusted for other covariates.



Portion Size Study



•Huizinga et al, Am J of Prev Med, 2009

Parental Health Literacy Activities Test (PHLAT)



Identifying Patients with Low Literacy



Assessing Literacy Status

- Not Reliable
 - Asking directly
 - Asking educational status
- Quick Techniques
 - Pill bottle
 - Signing name
 - Red Flags (Missed Appts, noncompliance, etc)
- Validated Techniques
 - REALM
 - TOFHLA
 - The Newest Vital Sign
 - WRAT, SORT, PIAT

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Communicating: What can you do?

- Use low literacy and picture based materials
- Individualized education
- Teach concepts in a simplified manner
- Use teach back technique
- Shared goal setting
- Address cultural issues



Low literacy Information

- Most patient information is written at or above the 10th grade levels
- Low literacy materials can improve patient knowledge and outcomes.
- When making materials:
 - Avoid pathophysiology and jargon and focus on key concepts/actions.
 - Use figures to simplify text
 - Increase white space
 - Try to write for the 4th-6th grade level
 - Use SMOG, FRY, Flesh-Kincaid Methods to assess your materials

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Resources for Low Literacy Material

- Writing your own:
 - <u>http://www.pfizerhealthliteracy.com/</u>
 - <u>http://www.ama-assn.org/ama/pub/category/8115.html</u>
 - <u>http://www.chcs.org/resource/hl.html</u>
 - <u>http://www.usability.gov/</u>
- Available Materials:
 - <u>http://www.fda.gov/opacom/lowlit/englow.html</u>
 - <u>http://www.nlm.nih.gov/medlineplus/healthtopics.html</u>
 (click on easy to read)
 - www.niddk.nih.gov/health/eztoread.htm#dia
 - <u>http://diabetes.niddk.nih.gov/dm/a-z.asp</u>

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Sample Materials



Readability

- Over 40 formulas (ex. SMOG, Fry, Flesh-Kincaid)
- Focus on word difficulty (syllables) and sentence length
- Can test running text (prose), but not tables, graphs, word lists, etc.
- Can be done by hand (ex Fry) or with computers (ex. Word or <u>www.readability.info</u>)
- Readability formulas are available for other languages (ex. Spanish Chinese, Vietnamese)
- Goal: 4th to 6th grade if possible!

•Teaching Patients with Low Literacy Skills, Doak, Doak, & Root, 1996



Suitability Assessment of Materials (SAM)

.

1. CONTENT

- (a) Purpose is evident
- (b) Content about behaviors
- (c) Scope is limited
- (d) Summary or review included

2. LITERACY DEMAND

- (a) Reading grade level
- (b) Writing style, active voice
- (c) Vocabulary uses common words
- (d) Context is given first
- (e) Learning aids via "road signs"

3. GRAPHICS

- (a) Cover graphic shows purpose
- (b) Type of graphics
- (c) Relevance of illustrations
- (d) List, tables, etc. explained
- (e) Captions used for graphics

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4. LAYOUT AND TYPOGRAPHY

- (a) Layout factors
- (b) Typography
- (c) Subheads ("chunking") used

5. LEARNING STIMULATION, MOTIVATION

- (a) Interaction used
- (b) Behaviors are modeled and specific
- (c) Motivation—self-efficacy

6. CULTURAL APPROPRIATENESS

- (a) Match in logic, language, experience
- (b) Cultural image and examples

2 points for superior rating 1 point for adequate rating

- 0 points for not suitable rating
- N/A if the factor does not apply to this material

•Teaching Patients with Low Literacy Skills, Doak, Doak, & Root, 1996

Teaching Concepts

- Limit advice to key concepts. Focus on behaviors and actions
- Simplify concepts
- Focus on one concept at a time; partition information
- Use concrete terms and examples
- Make info culturally relevant and personal
- Avoid Jargon!



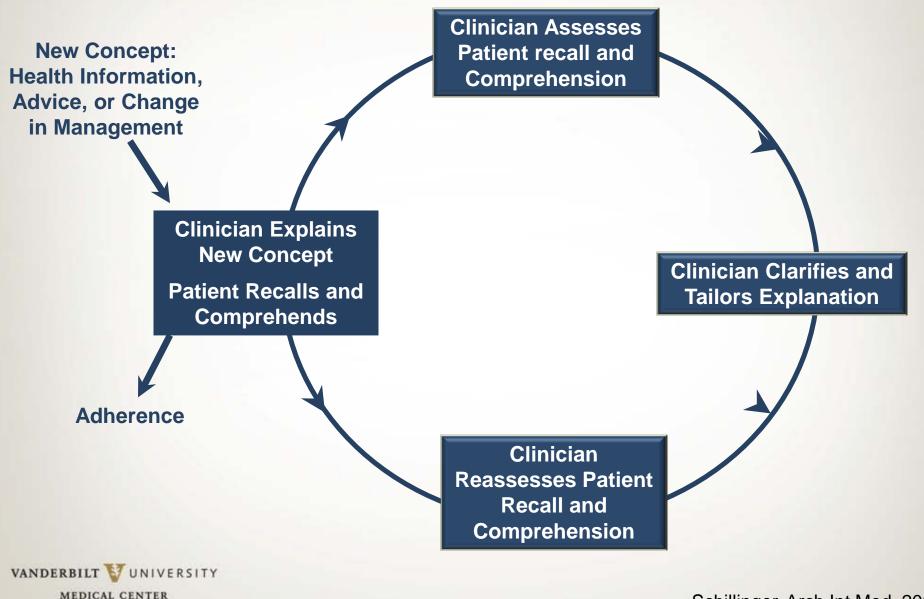
Avoid Jargon!

"Do you know what the number one cause for people in this country being on dialysis is? Diabetes"

Would you please tell me in your own words what <u>dialysis</u> means?	In your own words, what do you think the doctor was trying to tell the patient?
"Check something every day."	"Sugar is too high."
"What? Is that about you toes?"	"I can't say it."
"It means that your diabetes is going worse that you have to exercise to make diabetes."	"Means that more people are getting diabetes."
"You got to get on machine to pump redo blood to come up to par."	"That the sugar was nothmm."
"regarding kidney."	"Diabetes is one cause of kidney problems."
"That is a warningabout the kidneymy doctor told me about those side effects of the diabetes."	"About dialysis, because they are warning us, they are telling me about the complicationsthat if I'm having problems in my kidney, I'm going to have dialysis."
"It's a way to clean blood get off toxins out the blood."	"That you need to be on dialysis to cleanse blood or gonna die."
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Teachback technique



Schillinger, Arch Int Med, 2003

The role of feedback

Physician Variables, Stratified by Glycemic Control and Odds of Good Glycemic Control:

	HbA _{1c} L	evel, %	Unadju	Unadjusted Ac		djusted†	
	≤8.6	>8.6					
Predictor Variables	(n = 38)	(n = 23)	OR (95%CI)	P Value	OR (95%CI)	<i>P</i> Value	
Physician Variable				S			
Sex							
Female	19	15		05	0.04 (0.04 4.00)	00	
Male	19	8	0.53(0.18-1.55)	.25	0.21 (0.04-1.08)	.06	
Level of Training							
Attending physician	13	9	4 0 4 (0 40 0 04)	70	<u>_</u>		
Resident	25	14	1.24 (0.42-3.61)	.70 ‡			
Specialty							
Internal medicine	32	17	4 00 (0 40 0 00)		‡		
Family medicine	6	6	1.88 (0.43-8.20)	.33			
New concepts							
>1	25	14	4 0 4 (0 40 0 0 4)	70	‡		
1	13	9	1.24 (0.42-3.61)	.70			
Recall and comprehension as	sessed						
Yes	11	1	0.00 (4.07.74.00)	0.4	45 45 (2.07 440 70)	. 01	
No	27	22	8.96 (1.07-74.90)	.04 15.15 (2.07-110.78)		<.01	

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Schillinger, Arch Int Med, 2003

Cultural Challenges

Language

Limited English proficiency

- Family Structure

 Multiple caregivers
- Health Beliefs

Dissonance from the "biomedical model"

VANDERBILT WUNIVERSITY MEDICAL CENTER •Campinha-Bacote, 2003

Addressing Language Barriers

• Improve your language proficiency

• Use language-appropriate handouts

- Use a language interpreter ...
 - If you are not "natively fluent"
 - If you cannot "tell a joke" in that language



Working with an Interpreter

- Use only professionals
 - Not family members
 - Not other health-care providers

- Address the parent
 - Direct words and eyes toward the family

Respond to verbal and non-verbal cues



Improving the Consent and Measurement Process

- AHRQ Informed Consent Toolkit
- Use of Plain Language
 - Avoid jargons
 - Readability at 4th- 6th grade
 - Use of pictures to improve understanding
- Use of teach back to confirm understanding
- Proper translation of forms, and use of a translator



Literacy Interventions



Diabetes Intervention

 To examine whether literacy influences the effectiveness of a comprehensive diabetes disease management program to improve glycemic control.



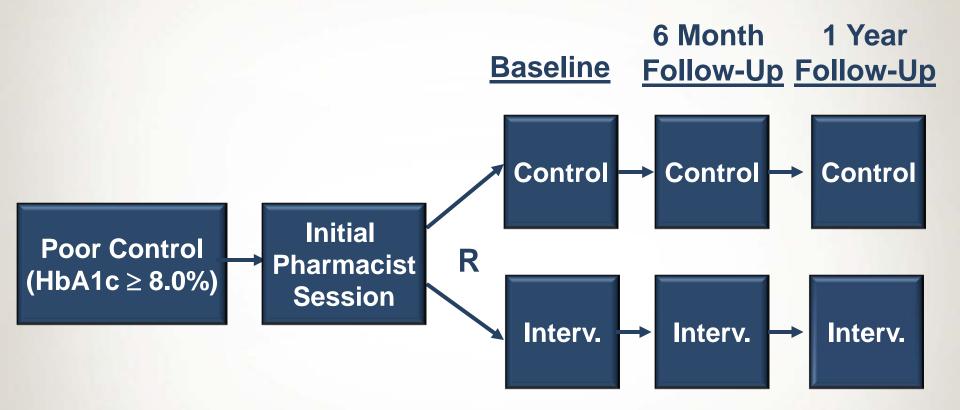
Rothman, JAMA, 2004 Rothman AM J Med, 2005

Methods

- Design: Examined literacy within a randomized controlled trial of intensive diabetes disease management program
- Duration: One year
- Setting: UNC general medicine clinic
- Population: Type 2 diabetes with poor glucose control (A1C ≥ 8.0%)



Methods: Enrollment Process



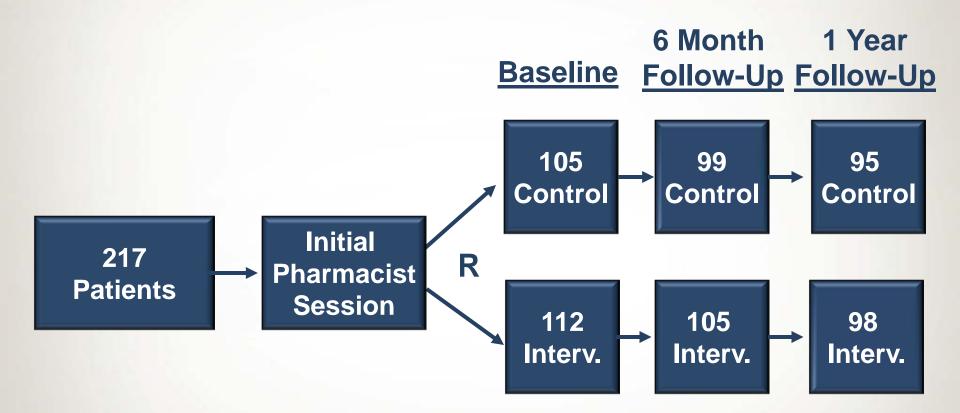


Intervention

- Diabetes Education
- Evidence-based medication algorithms
- Database to track and manage patient outcomes
- Diabetes Care Coordinator
- Addressed literacy by using:
 - Individualized verbal education
 - Low literacy material
 - Teaching concepts in a simplified manner
 - "Teach back" techniques to confirm learning

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Results: Study Flow





Similar Patient Characteristics

Variable	Control (n=105)	Interv. (n=112)
Female	56%	56%
Age	57 yrs	54 yrs
African American	60%	69%
Household Income ≤ \$20,000	75%	70%
Less than a High School Education	44%	36%



Similar Diabetes Measures

Variable	Control	Interv.
	(n=105)	(n=112)
Baseline A1C (%)	10.7	10.9
Duration of Diabetes	8.6 yrs	8.1 yrs
Use of Insulin at Enrollment	38%	40%
Hypertension	82%	83%
Hypercholesterolemia	63%	60%



Similar Literacy

Variable	Control (n=105)	
Realm Score (0-66)	46	45
Low Literacy (≤ 6 th Grade)	32%	44%



Significant Clinical Improvements at 12 mos

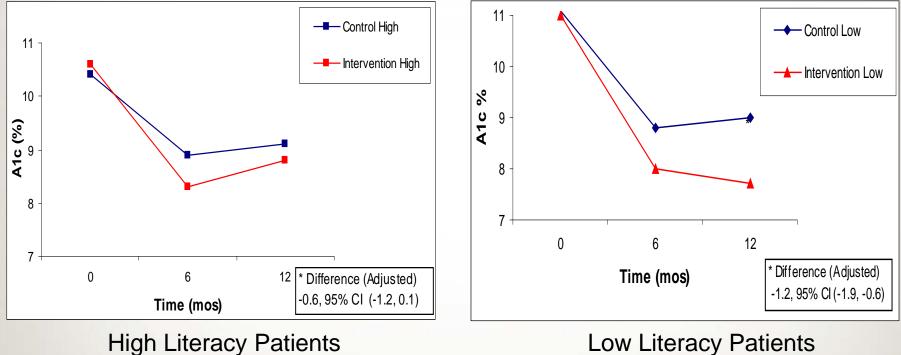
Variable	Control (n=95)	Intervention (n=98)	Difference	
A1C (%)	-1.2%	-2.1%	0.9% (0.8,1.0)	
SBP (mmHg)	+2.3	-6.9	9.2 (2.3,16.1)	
DBP (mmHg)	+1.2	-3.6	4.8 (1.1,8.6)	
ASA (mmHg)	+6%	+47%	41% (25-55)	
T. Chol. (mg/dL)	-12	-27	15 (-4, 35)	

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Impact on Literacy



Influence of Patient Literacy on the Effectiveness of a Primary Care–Based **Diabetes Disease Management Program**



Low Literacy Patients



Diabetes and Numeracy RCT



DLNET Study Results

A1c	3-months	Adjusted p-value [Intervention vs. Control]*	6-months	Adjusted p- value [Interventio n vs. Control]*
Intervention	-1.63 [-2.03 , -1.23]	0.03	-1.11 [-1.54,-0.65]	0.437
Control	-0.97 [-1.37 , -0.53]		-1.17 [-1.61,-0.71]	

Mean [95% bootstrap Confidence Interval]

*Adjusting for age, gender, race, type of diabetes, income level, site of intervention and baseline DNT score and Hba1c levels

 In adjusted analyses, there were no significant improvements in Self-Efficacy or Self-Management behaviors

Cavanaugh KL et al. Diabetes Care 2009



CHF Randomized Trial

http://www.shareddecisionmaking.org

VANDERBILT WUNIVERSITY MEDICAL CENTER DeWalt et al. *Patient Educ Couns.* 2004;55(1):78-86 DeWalt et al. BMC Health Services Research. 6:30; 2006.

NIH (NIDDK) R18 Study

- To address health communication issues to improve diabetes care in middle TN
- 5 year cluster randomized study involving 10 Health Dept Clinics
- Collaboration between TN Department of Health, Vanderbilt, and Meharry



National Initiative (GreenLight)

- Project supported by NIH (NICHD). Collaboration between Vanderbilt, UNC, NYU, and UMiami
- Will enroll 1,000 English and Spanish speaking families with children age 2 months and follow for 22 months. Intervention sites will focus on obesity prevention, while control sites will focus on injury prevention.
- Will train intervention Pediatric providers in improved health communication skills and give them a literacy sensitive toolkit to use with families to promote healthy lifestyles for their children.



Native American Research Center for Health (NARCH)

- IHS/NIH. PIs Hayes (USET), Bernard(VU).
 Project PIs: Schlundt and Rothman
- First NARCH serving NA in Eastern US
- CBPR project using health information technology (HIT) to improve diabetes care
 - People with diabetes
 - Health care providers: Reduce complexity of using computer technology
 - Tribal leaders: Better access to information about tribal health & improved ways to communicate with tribal members about health issues
- Opportunity to develop additional projects and training component



Overall Conclusions

- Low literacy/numeracy and poor health communication are common barriers to quality health care and participation in research
- Even patients with high literacy skills can struggle to navigate our complex system and perform self-care
- Interventions that improve communication and address literacy issues can improve quality of care and participation in research

Questions







Community-Engaged Research

September 26, 2011

An OHRP National Research Community Forum

C O - S P O N S O R S Office for Human Research Protections Washington University School of Medicine in St. Louis Meharry Medical College

September 27, 2011

Community-Engaged Research Conference

C O - S P O N S O R S Washington University School of Medicine in St. Louis Meharry Medical College Washington University Institute of Clinical and Translational Sciences



Exploring the Unique Community-Academic Relationship

•If you have a question,

•raise your hand and•wait for the microphone

•or

•write your question and pass it to

a conference assistant.



