

Literacy and Adherence

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A Clinic Visit

- 54 y.o. woman with DM and HTN returns to clinic 3 months after your last visit
- At the last visit, her A₁C was 11.2% and her BP was 164/82. She was taking Glipizide 10 QD and Enalapril 10 mg QD.
- You added Metformin 500mg bid and HCTZ 25 mg QD
- Today she returns to clinic and her A₁C is 11.3%; BP is 160/85.



Goals

- Review importance of adherence for managing chronic conditions
- Review relationship between low literacy and adverse health outcomes
- Examine the complex relationship between literacy and adherence
- Describe a successful intervention for patients with low literacy and heart failure

Key Messages

- Adherence can be difficult, but it is essential for realizing treatment benefits
- Low literacy is associated with a variety of adverse health outcomes, including increased morbidity and mortality
- To date, it is not clear if, and how much, adherence mediates the relationship between low literacy and adverse outcomes
- Interventions that build self-care skills can overcome literacy-related health disparities



Adherence



- What is Patient Adherence?
- Why does adherence matter?
- What factors affect adherence?
- Literacy and adherence
- How Can We Improve Adherence?





What is Adherence?

- **Compliance:** “the extent to which a person’s behavior coincides with medical or health advice”
-Haynes, 1979
- **Adherence:** “the extent to which the patient continues an agreed-upon mode of treatment (under limited supervision) when faced with conflicting demands”
-American Heritage Medical Dictionary 2007

Types of Medication Non-adherence

- Not filling the prescription
- Taking a different dose
- Taking at a different time
- Missed, skipped, or extra doses
- Early discontinuation

Prevalence of Non-adherence

- On Average, Patients with Chronic Illness Take Only 50% of Prescribed Doses

- TB: 48% pts miss Rx \geq 2 mos.
Pablos-Mendez, Am J Med, 1997.

- Hypertension: 50-60% near-optimal adherence.
Rudd P, Am H J. 1995.

- Antilipidemics: 50% of patients took 1/4 to 1/2 dose.
LRCP. JAMA 1984.

- ART: Patients take 53%-79 % of prescribed doses.

- Bangsberg AIDS 2000
- Arnsten CID 2001
- McNabb CID 2001

- Gross AIDS 2001
- Liu Annals Int Med 2001
- Paterson Annals Int Med 2000

- Metaanalysis: 40% of patients take all of prescribed doses.
Roter et al. *Medical Care*. 1998; 36: 1138 - 1161.

Adherence Measures

No “Gold Standard”

- Blood levels or Urinary excretion
- Outcome measures (e.g. A1C)
- Patient or family member report
- Provider estimate
- Prescription refill records
- Pill counts
- Electronic caps (e.g. MEMS)



Morisky Score

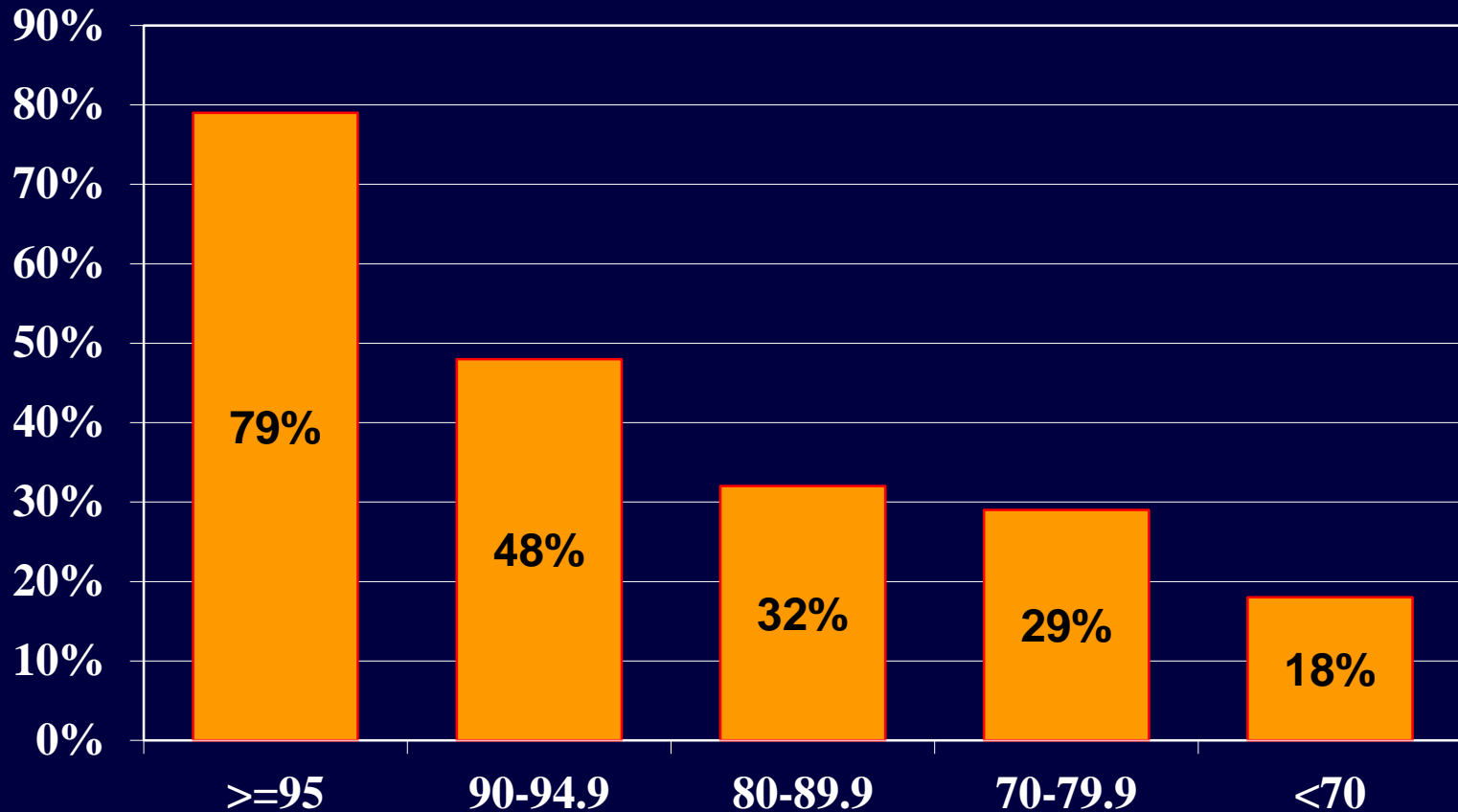
- 4-question patient survey
 - Do you ever forget to take your medication?
 - Are you careless at times about taking your medication?
 - When you feel better, do you sometimes stop taking your medication?
 - Sometimes if you feel worse when you take your medication, do you stop taking it?
- Non-adherence = “yes” to 2 or more questions (61% sensitivity c/w claims data)
- “Positive” response linked with poorer A1C



How much Adherence is Enough?

% undetectable viral load

N =91



Adherence to HAART measured for 6 mos (%)



ART Adherence Matters

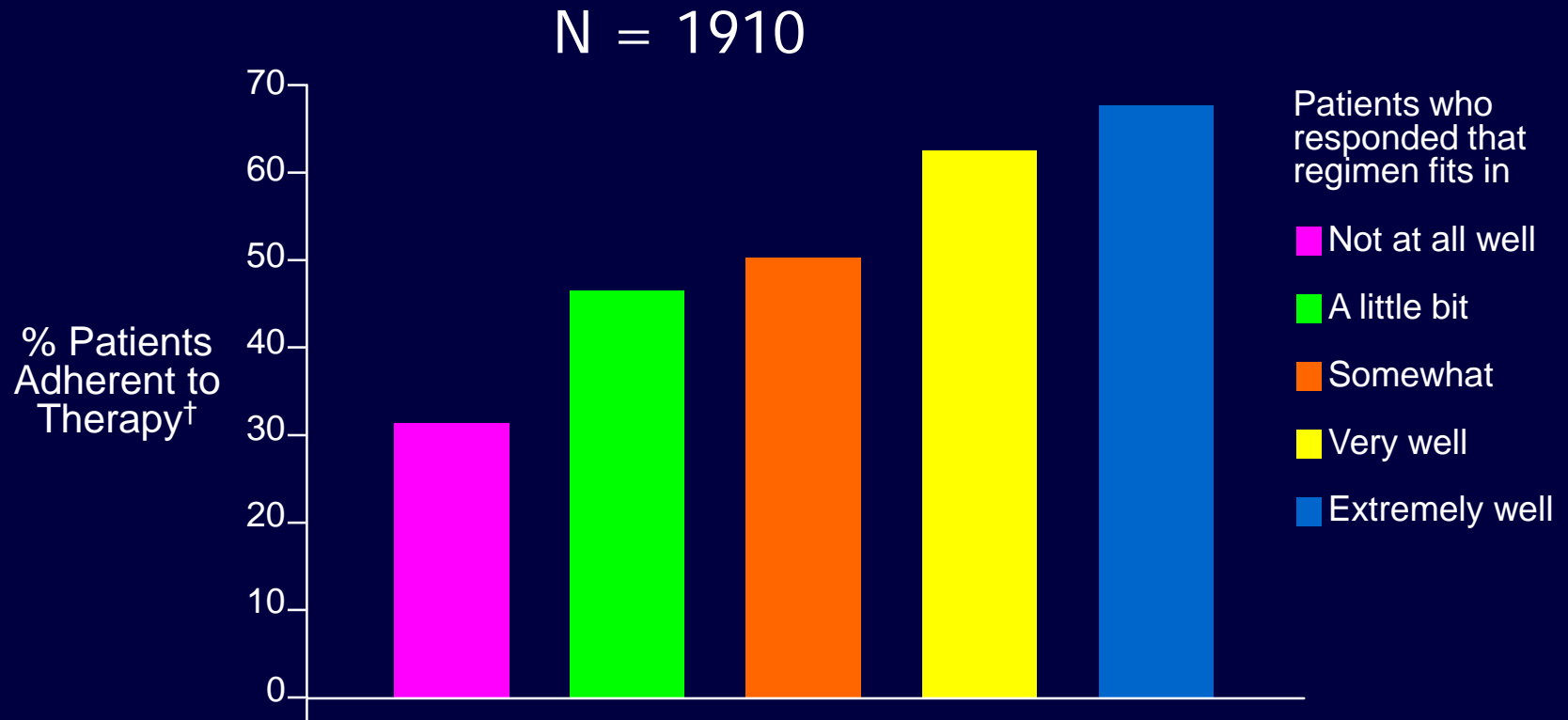
- Lower adherence associated with:
 - higher viral loads / lower CD4 counts
 - increased risk of hospitalization
 - increased progression to AIDS
 - increased mortality

Arnsten J, et al. 7th CROI, 2000; Bangsberg DR, et al. AIDS 2000; Bangsberg et al., 8th Conf on Retroviruses, 2001; Hogg, et al, 7th CROI, 2000; Patterson, An Inter Med, 2000; Singh N, et al. Clin Infect Dis 1999.

Factors Affecting Adherence: 4“P”s

- **PAIENT**: lack of symptoms, psychiatric illness, poor skills, poor understanding, cognitive impairment, **literacy**, substance misuse / abuse.
- **POTION**: side effects, complexity, cost
- **PROVIDER**: trust, relationship, beliefs, knowledge
- **PLACE**: daily activities, pharmacy access, housing, social support, reminders

Correlation of Adherence With Regimen Fit with Patient's Daily Life*



* $P < .001$.

†Patients who reported no missed doses in the past week.

Data from Wenger et al. Poster presented at: 6th Conference on Retroviruses and Opportunistic Infections; January 31–February 4, 1999; Chicago, Ill. Poster 98.

Prescribing Recommendations

- Ask preferences; **tailor regimen** to pt needs
- Assess **readiness** (prior experience with medicine)
- Assess / **treat depression and substance misuse**
- **Inform (what and why)** using literacy-sensitive “teach back” methods
- **Assess comprehension**
- Give them **someone to call** with questions



At Return Visits

- **Ask** open-ended, non-judgmental questions

“What’s it been like for you taking your medicine?”

“How well does the regimen fit in your daily routine?”

“How confident are you that you can take these the way I am recommending in the next 30 days?”

- Help them **identify barriers** and facilitators

“What gets in the way for you? What helps you remember?”

- Assess and **manage/address side effects**

- Help them identify available **social support**

- Enhance self-efficacy with **goal setting**, reinforcement, **cues** and reminders



Vulnerable Populations

- Elderly
- Low income
- Poor social support
- Lack of patient/family knowledge about disease
- Depression
- Lack of transportation
- No access to medications
- English as a second language
- **Low literacy**

Literacy

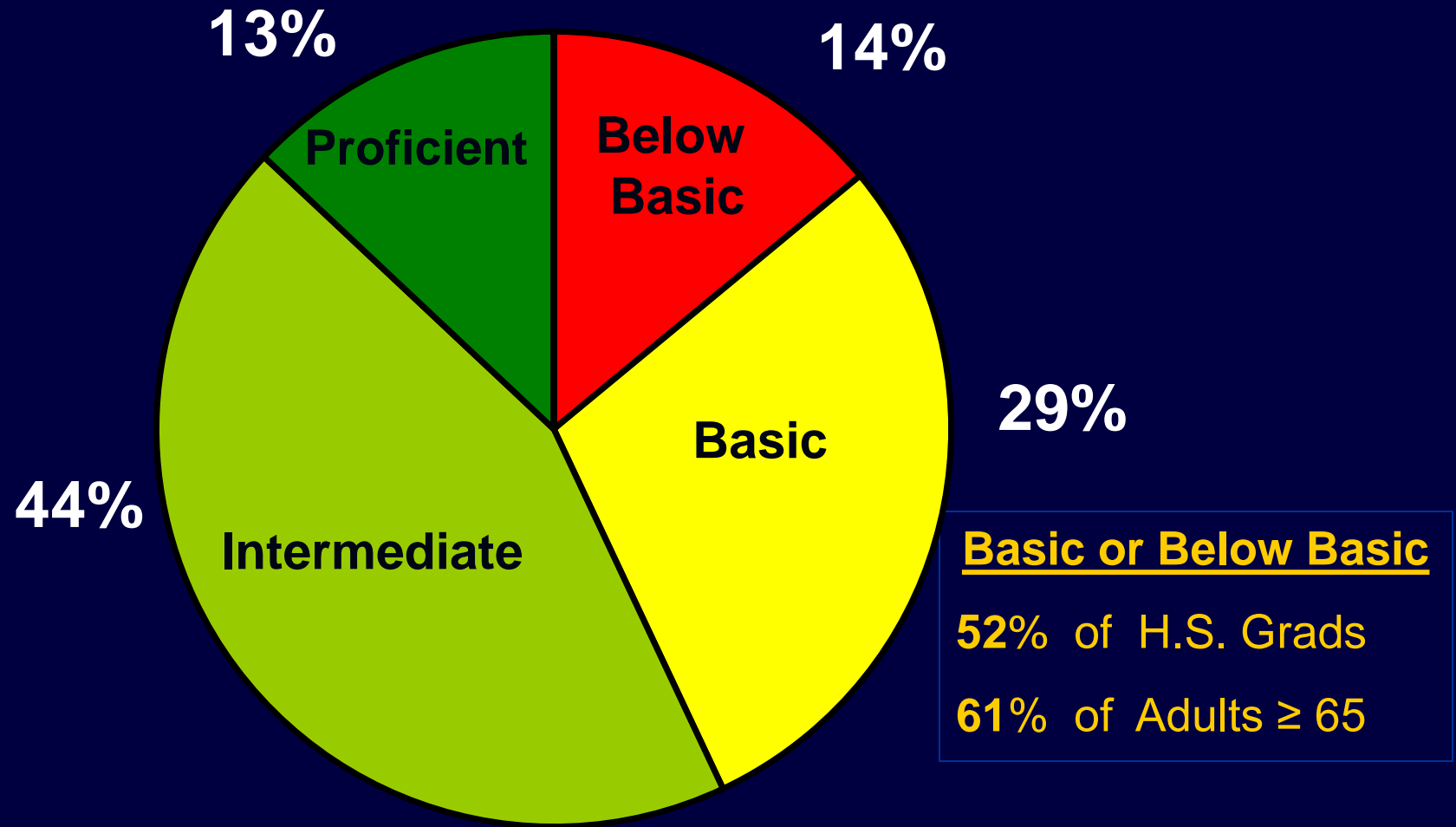


National Assessment of Adult Literacy (NAAL)

- Most up to date portrait of US literacy
- Scored on 4 levels
- Lowest 2 levels cannot:
 - Use a bus schedule or bar graph
 - Explain the difference in two types of employee benefits
 - Write a simple letter explaining an error on a bill

National Center for Education Statistics, U.S. Department of Education

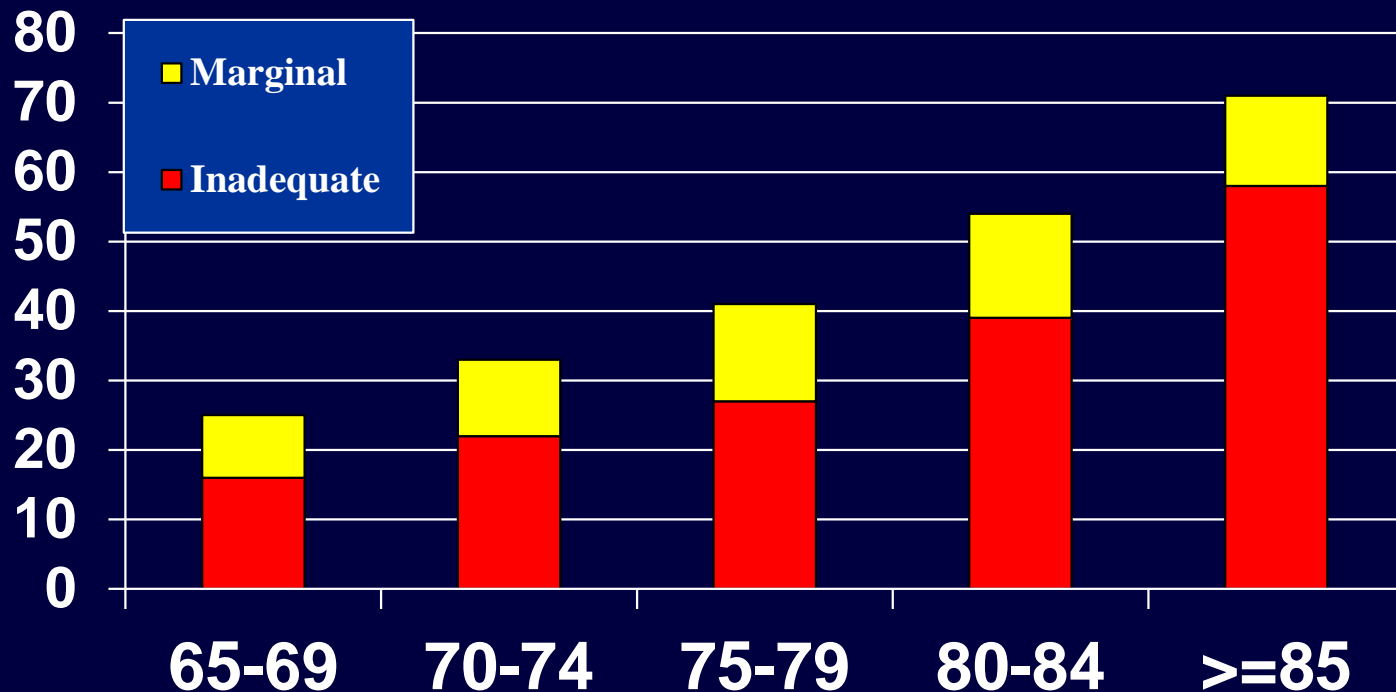
2003 National Assessment of Adult Literacy



93 Million Adults have Basic or Below Basic Literacy



Inadequate Literacy Increases with Age



Baker et al. J Gerontol B Psychol Sci Soc Sci. Nov 2000;55(6):S368-374.

Health Outcomes Associated with Literacy

Health Outcomes/Health Services

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

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
- Prescription labels

DeWalt, et al. JGIM 2004;19:1228-1239



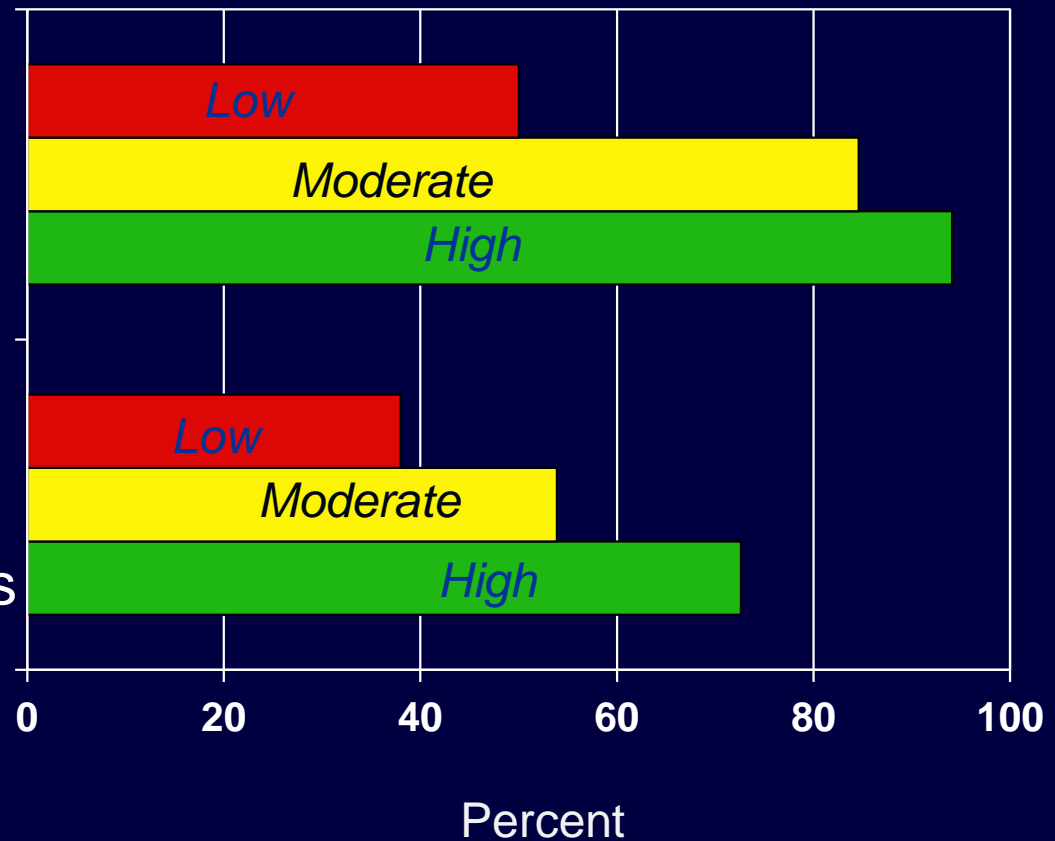
Patients with Diabetes and Low Literacy Less Likely to Know Correct Management

Need to Know:

symptoms of low blood sugar (hypoglycemia)

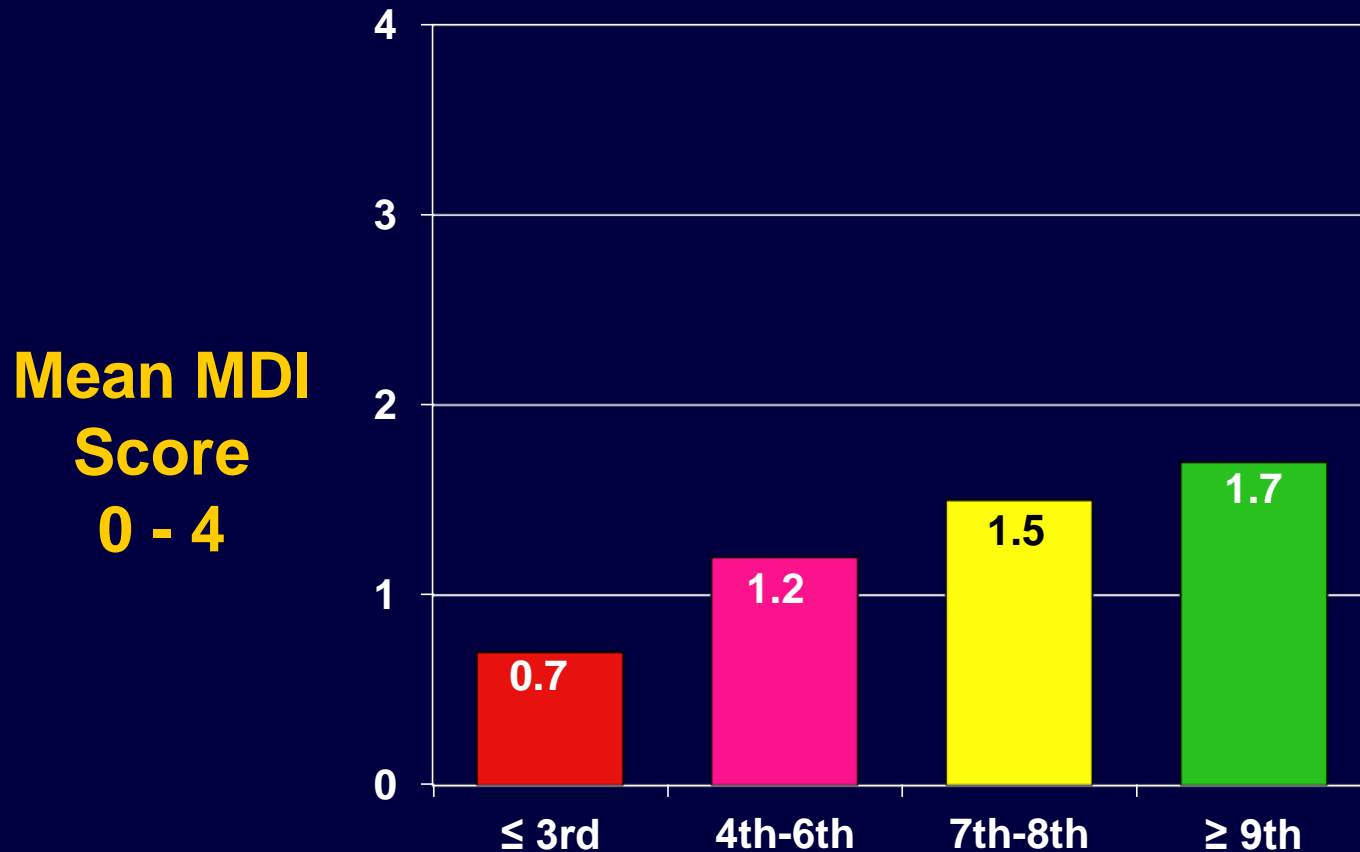
Need to Do:

correct action for hypoglycemic symptoms



Williams et al., Archive of Internal Medicine, 1998

Asthma Patients with Low Literacy have Poorer Metered Dose Inhaler (MDI) Skills



Williams et al. *Chest* 1998, 114(4):1008-1015.



Adult Hospitalization

- People with low literacy have 30-70% increased risk of hospitalization
- RR = 1.29 (1.07-1.55) Medicare Managed Care
- RR = 1.69 (1.13-2.53) Urban Public Hospital

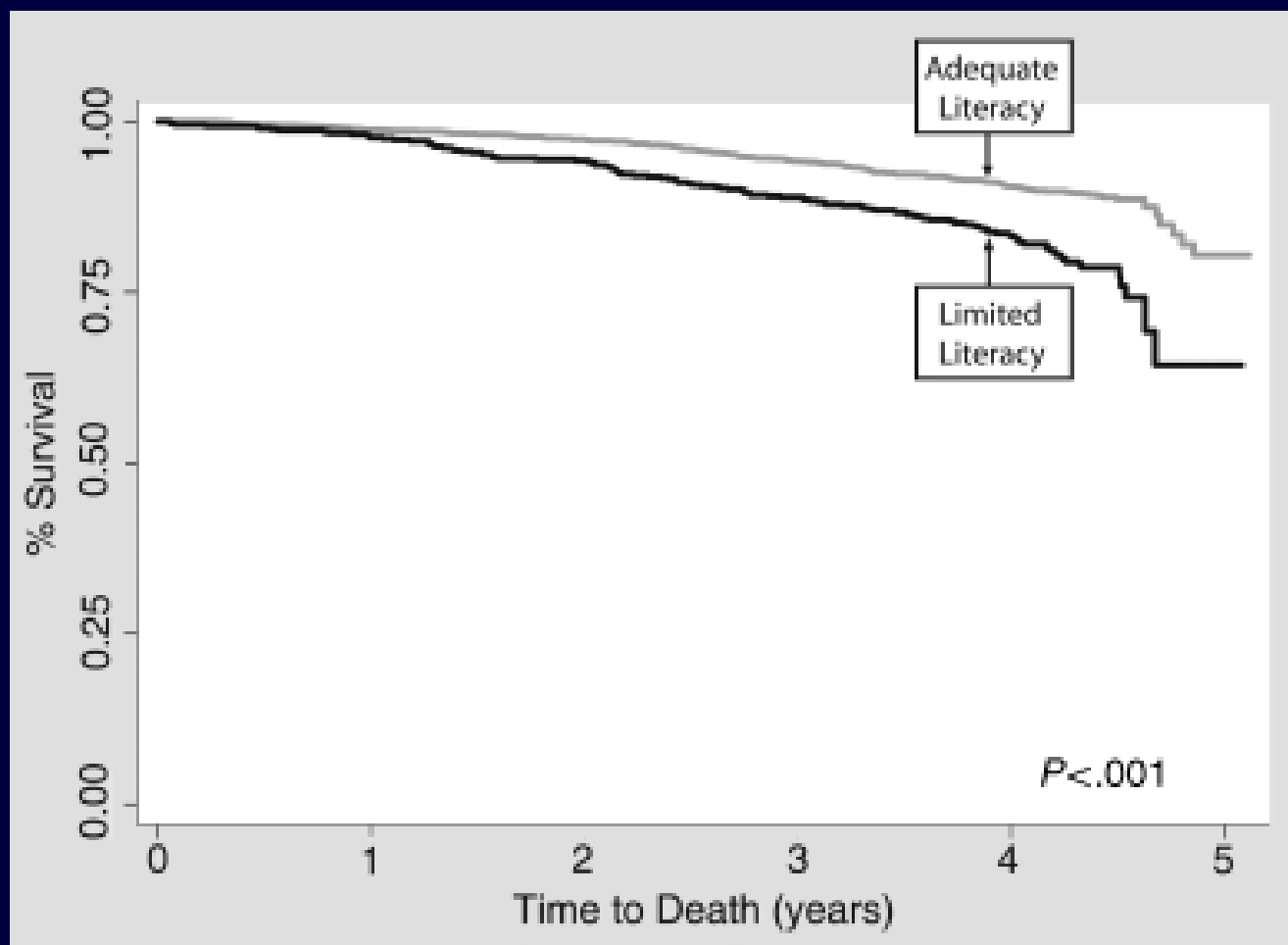
*Adjusted for age, gender, socioeconomic status, health status, and regular source of care.

Baker et al. AJPH. 2002. 92:1278.

Baker et al. JGIM. 1998. 13:791.



Literacy and Mortality



Health, Aging, and Body Composition Study

Sudore et al. JGIM 2006; 21: 806-812



Literacy and Adherence

Relationship Between Literacy and Adherence is Complex

- Mixed findings for ART adherence and diabetes
- No effect for anticoagulation
- Low literacy may make initial adoption harder, but may have neutral or positive effects once a behavior is in place
- Effect may differ across conditions

Fang JGIM 2006; 21: 841-6; Golin JGIM 2002; 17:756-65; Kalichman JGIM 1999; 14: 267; Rothman Annals 2008; 148:737-46; Schillinger JAMA 2002; 288: 475-82; Pignone and DeWalt JGIM 2006; 21: 896-7.

Literacy and Heart Failure

Heart Failure Epidemiology

- 4.8 million people in U.S. have heart failure
- Leading cause of hospitalization in elderly
- Of those hospitalized, 25% to 50% are re-admitted within 3-6 month
- Half of all admissions are preventable
- Self-care, including adherence, essential
- 13% of Medicare enrollees, 37% of Medicare expenditures

Individuals with lower literacy are more likely to:

- Be diagnosed with HF
- Experience hospitalization due to HF
- Die due to HF complications

Heart Failure Organized Care Programs

- 29 randomized trials
- Three types:
 - Multidisciplinary team care (n =15)
 - Telephone-based care (n = 10)
 - Self-care training (n = 4)
- All types reduced HF-related hospitalizations
- 15 of 18 studies reported cost savings
- No information on the role of participant education or literacy

McAlister JACC 2004; 44:810

Components of Successful Heart Failure Programs

- Multidisciplinary teams
- Defined follow-up procedures
- Treatment algorithms based on best available evidence
- Information systems for tracking patients
- Patient education for self-care

Self-care Training

- 4 trials
- Number of participants 88-192
- Mean age 71-76
- Follow-up 1 week – 12 months
- HF hospitalizations: RR 0.66 (0.52, 0.83)
- All hospitalizations: RR 0.73 (0.57, 0.93)

McAlister JACC 2004; 44:810

Recent Studies: Sisk trial

- 406 adults in NYC followed for 12 months
 - 78% minority
 - mean age 59
 - 30% low literacy
 - All with systolic HF (EF < 40%)
- Nurse-led self-care training
 - Regular phone follow-up
 - Facilitation of medication changes
- 12 month outcomes:
 - Reduced hospitalization rate (- 0.13 / person-yr)
 - Improved QOL (3.1 points on SF-12; 4.7 on MLHF)



Murray Trial

- 314 adults with HF
- Intervention vs. usual care
- Multi-disciplinary team approach
- Intervention improved adherence (79% vs. 68%, measured by MEMS)
- 18% reduction in incidence of ED visits and hospitalizations
- \$3000/year reduction in direct costs

Murray et al Annals of Internal Medicine 2007; 146:714



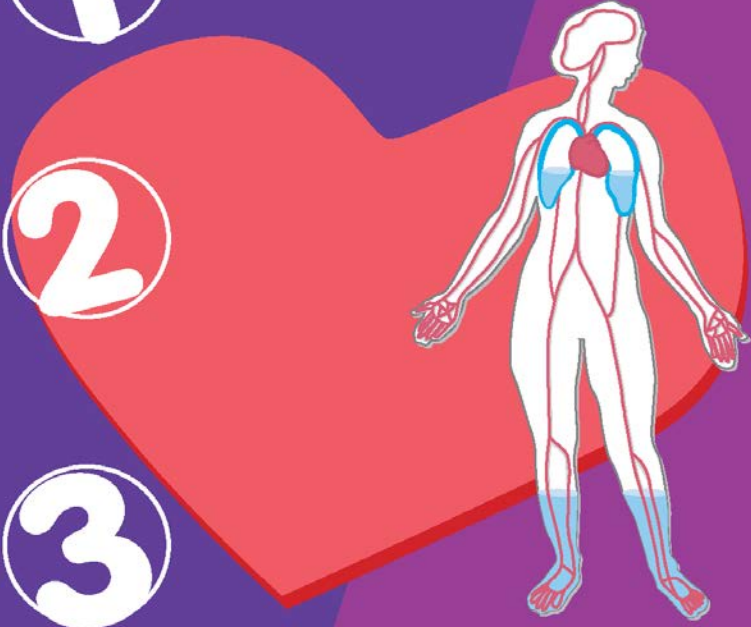
Our Research at UNC

MANAGING YOUR HEALTH
WITH HEART FAILURE

1

2

3



UNC School of Medicine and Department of Pharmacy (Working Group on Health Risk Communication) 919-843-6480

The image is a poster titled "MANAGING YOUR HEALTH WITH HEART FAILURE". It features a teal header with the title in white and purple text. Below the title, there are three numbered circles (1, 2, 3) on the left side. In the center, there is a large red heart shape. To the right of the heart is a white anatomical diagram of a human figure showing the circulatory system, with the heart and major vessels highlighted in blue and red. The background is a gradient of purple and teal. At the bottom, there is a line of text providing contact information for the UNC School of Medicine and Department of Pharmacy.



Our Intervention

- 1-hour individual education session
- Education booklet <6th grade level
- Digital bathroom scale
- Scheduled follow-up phone calls
- Easy access to care team

Development of Educational Materials

- Distilled to essential information
- Collaborated with medical illustrator
- Focus group feedback
- Cognitive interviews
- Revised materials

Information Recommended by Guidelines

- General topics
- Explanation of heart failure
- Expected symptoms vs. symptoms of worsening heart failure
- Psychological responses
- Self-monitoring with daily weights
- Action plan in case of increased symptoms
- Prognosis
- Advanced directives
- Dietary recommendations
- Sodium restriction
- Fluid restriction
- Alcohol restriction
- Activity and exercise
- Work and leisure activities
- Exercise program
- Sexual activity
- Medications
- Nature of each drug and dosing and side effects
- Coping with a complicated regimen
- Compliance strategies
- Cost issues

Grady et al. *Circulation*. 2000;102(19):2443-2456.



Information We Included

- *General topics*
- Explanation of heart failure
- Expected symptoms vs. symptoms of worsening heart failure
- *Psychological responses*
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DeWalt et al. Patient Ed Coun. 2004; 55: 78



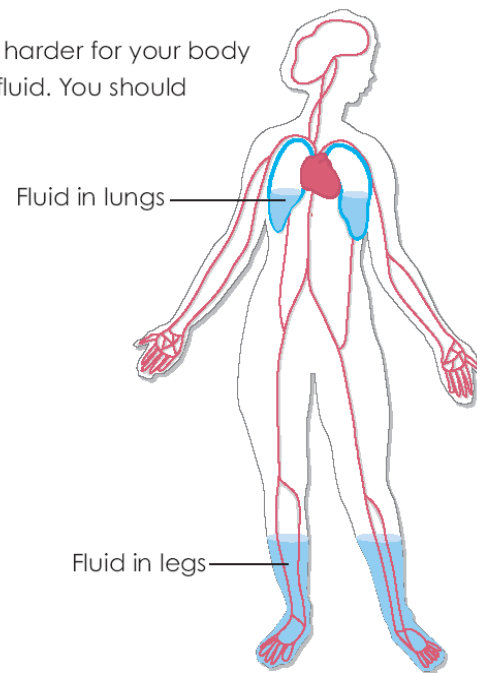
Congestive Heart Failure

With congestive heart failure, the heart cannot pump the blood well. As a result, blood doesn't flow well.

Fluid leaks out of your blood vessels and backs up in the lungs and the legs.



Salt makes it harder for your body to get rid of fluid. You should avoid salt.



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

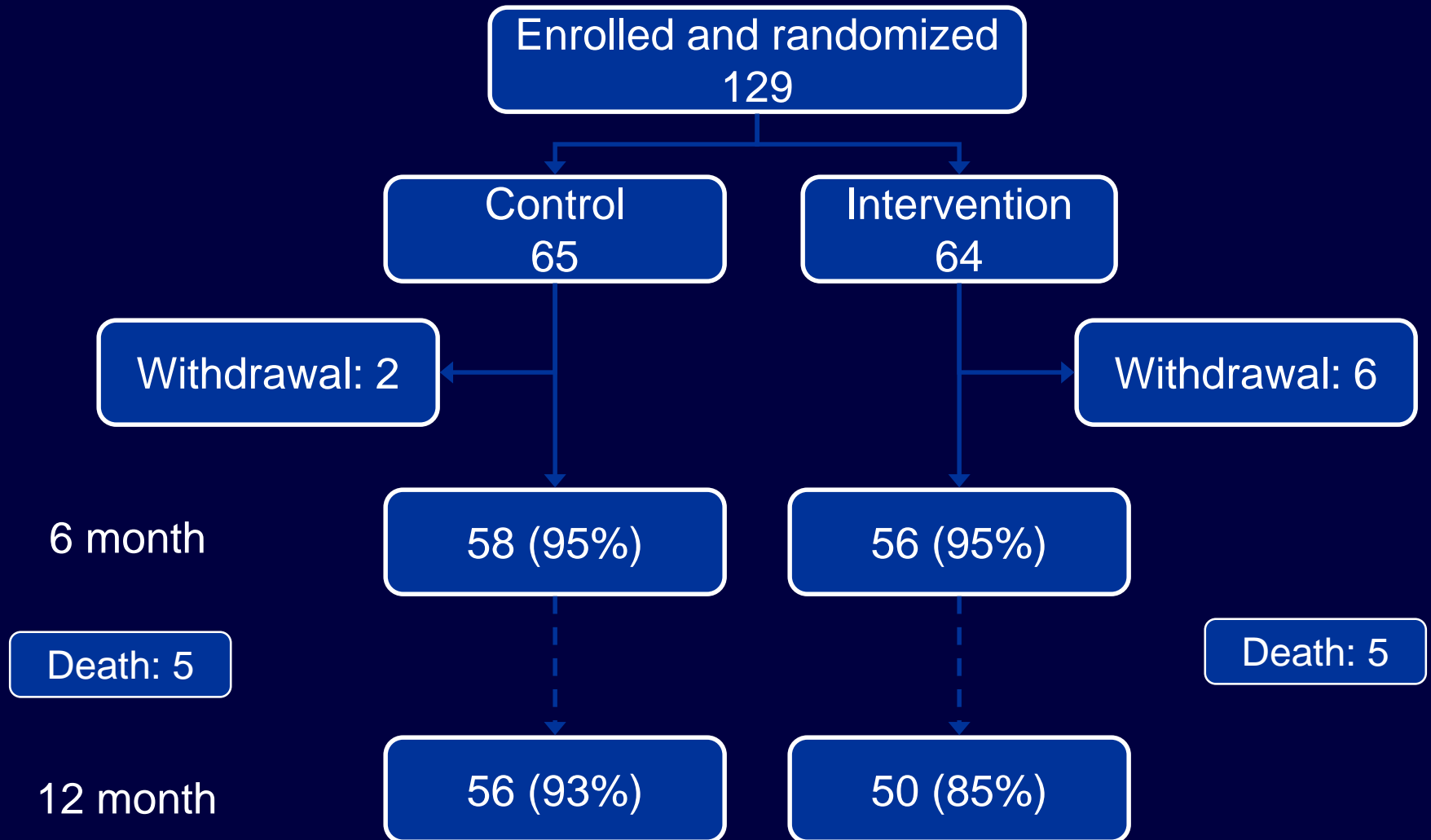


Randomized Trial

- UNC Internal Medicine and Cardiology
- Self-care training vs. usual care/ booklet
- 1 year duration
- Primary Outcome: incidence of hospitalization or death
- Secondary Outcomes:
 - HF-related quality of life
 - HF knowledge
 - HF specific self-efficacy
 - HF self-care (adherence to daily weight)



Enrollment and Follow-up



Baseline Characteristics

Variable	Control (n=65)	Intervention (n=64)
Mean Age, years	62	63
African American, %	55%	56%
Male, %	42%	58%
Education, years	9.8 + 2.8	9.1 + 3.2
Income <15K/yr, %	68%	69%
Medicaid, %	32%	36%
Medicare, %	73%	72%
Literacy (S-TOFHLA) Inadequate, %	40%	45%

Improved HF Knowledge, Self-Efficacy, and Self-Care Behavior

6 Month Outcome	Control	Intervention	Difference (CI)
Knowledge change	-2	10	12 (4, 19)
Self-efficacy change	-0.5	1.3	2 (0.5, 3.1)
Daily weight measurement, %	21	88	67 (53, 81)

Reduced Incidence of Hospital Admission or Death

- Overall:
0.56 [0.32, 0.95]
- Low literacy sub-group:
0.38 [0.16, 0.88]

DeWalt et al BMC Health Serv Res. 2006 13:30

How Well did Patients do with Materials?

- 56 patients completed 6 months of intervention
- Low literacy patients **more** likely to use the log sheets: 92% vs. 71%, $p=0.05$

Adherence to Instructions -- Errors

	Inadequate Literacy	Adequate/Marginal Literacy
Weeks 3-7 Mean errors	6.7	3.6
Weeks 18-22 Mean errors	3.6	4.2

Conclusions of Adherence Analysis

- Low literacy patients more likely to use materials
- Low literacy patients are less successful early after instruction, but improve over time
- Learning requires multiple sessions!



The End

Last updated 12.09.08

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