

## **Health Literacy and Patients with Prostate Cancer**

**Satellite Conference and Live Webcast  
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## **Faculty**

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## **A Recent Email**

**YES MY NAME IS XXXXXXXXXXXX. MY DOB IS 00-00-79 I AM WRITIN ON BEHAVE OF MY SELF N MY DOCTOR XXXXXXXXXXXX. I went n seen him on 03-31-08 n he wants to know what i would have to do to get the surgery done for me beein over weight i want to know who i can go to for it he says there are doctors in mobile who can do it when you find out for me please call me at 251-000-0000 or at my moms 251-000-000 or his office at 251-000-0000 thank you very muck (name)**

## **FDA Issues Advisory for Spiriva and Foradil**

- **Date posted: February 29, 2008**
- **The FDA has issued a public health advisory highlighting the correct use of Spiriva (tiotropium bromide inhalation powder, from Boehringer Ingelheim) and Foradil (formoterol fumarate inhalation powder, from Schering-Plough) capsules**

## **FDA Issues Advisory for Spiriva and Foradil**

- **The FDA and the National Poison Control Center have received many reports of patients swallowing Foradil and Spiriva capsules rather than placing the capsules in the inhalation devices**

## **Defining Literacy**

- **Functional literacy**
  - **The ability to read, write, and speak in English, to compute and solve problems, to be able to function on the job and in society, to meet goals, and develop knowledge and potential**

### **Defining Health Literacy**

- In the report Healthy People 2010
  - Health literacy is defined as: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”

### **Defining Health Literacy**

- Health literacy
  - Is context critical – even well-educated adults struggle with health concepts, terms and systems
- Health literacy involves several skills
  - Reading, understanding, and analyzing information

### **Defining Health Literacy**

- Performing basic numerical and computational tasks
- Decoding instructions, diagrams, and symbols
- Weighing risks and benefits
- Making decisions and taking action

### **Defining Health Literacy**

- Functional health literacy
  - Impacts patient’s ability to access services and communicate with providers
  - Can lead to
    - Lack of trust and honesty between patient and provider
    - Errors and misinformation
    - Higher costs to patient and practice

### **Literacy in the US**

**1/2**

- US adult population suffers from low literacy

### **Literacy in Alabama**

- Statewide
  - 15% of adults do not read
- Literacy improved between 1992 (21%) – 2003 (15%)
- Closer to national rate of 14.5%
- Birmingham Metro
  - 90,000 functionally illiterate

### **Literacy in Alabama**

- There is a clear link between low literacy and poverty levels
  - Individuals with low literacy skills usually have difficulty with everyday tasks such as filling out job applications, locating intersections on street maps, finding information contained within newspaper articles, reading a bedtime story to their children, or following directions on prescriptions and medicine bottles

### **Who Suffers from Poor Literacy?**

- Groups more likely to have low or marginal literacy skills, according to the 1992 National Adult Literacy Survey
  - Low income
    - 43% of individuals with low literacy live in poverty

### **Who Suffers from Poor Literacy?**

- 70% have either no job or only a part-time job
  - Seniors
    - More than 1/3 of English-speaking seniors had marginal health literacy skills

### **Who Suffers from Poor Literacy?**

- Non-english speakers
  - Less than half claiming to need a translator during office visits had access to one

### **Who Suffers from Poor Literacy?**

- Chronically ill
  - Literacy skills are a strong predictor of a patient's knowledge of their disease
  - Stress, care giving demands can impact health literacy

### **Who Suffers from Poor Literacy?**

- Immigrants
  - 15% of the functionally illiterate were born outside the US
- Learning disabilities
  - 5% of the functionally illiterate have learning disabilities
  - Includes dyslexia, perception or processing disabilities

### **Poor Literacy Creates Health Risks**

- Patients don't understand and cannot act on the health information doctors give them
- Physicians may incorrectly interpret low health literacy as lack of compliance

### **Poor Literacy Creates Health Risks**

- Barriers for patients
  - Lack of familiarity with terms and systems
  - Illness and/or medication – can impair understanding
  - Stress and fear – adrenaline rush blocks learning

### **Why Patients Are At Risk**

- Increasingly complex healthcare system
  - Growing requirements for self-care
  - More medications
  - More tests and procedures
  - Medical jargon
  - Reliance on written patient instruction

### **Why Patients Are At Risk**

- An aging population
- A more culturally diverse patient population

### **Impact of Low Health Literacy**

### **Consequences of Low Health Literacy**

- Low health literacy leads to
  - Lower health knowledge
  - Unhealthy behaviors
  - Poorer health outcomes
  - Greater health costs

### **Low Literacy in Patients**

- **May not always be evident**
  - Patients often hide facts
  - Patients have learned to compensate on the job
- **At time of visit**
  - Patient may not understand what to do
  - Patient may leave rather than admit they cannot fill out forms

### **Quality of Care Is Compromised**

- **Low health literacy compromises the quality of health care**
  - Poor communication with physician/nurse
  - Inaccurate patient history may be given

### **Quality of Care Is Compromised**

- Patient may be unable to give informed consent for procedures and/or studies
- Misunderstandings can result in lawsuits

### **Impact of Low Literacy on Self-care**

- **Self-care incomplete**
- **Serious medication errors in self administration**
- **Poor sterile technique**
- **Noncompliance can actually be a lack of understanding**

### **Health Literacy and Prostate Cancer**

- **Low literacy can**
  - Hinder prostate cancer treatment
  - Result in misunderstandings leading to poor outcomes; lawsuits
  - Make it difficult to assess side effects, outcomes

### **Health Literacy and Prostate Cancer**

- **Issues unique to prostate cancer screening and treatment**
  - Low literacy individuals may have difficulty with complex decision-making related to testing / treatment issues

### **Health Literacy and Prostate Cancer**

- Not all patients comfortable making decisions
  - May leave it to physician rather than risk misunderstanding
- Significant percentage of patients do not understand basic medical terms and cannot identify key anatomic structures/functions

### **Health Literacy and Prostate Cancer**

- Issues related to screening/treatment
  - Need for informed decision-making for screening
  - Limitations of PSA testing frequently not discussed when tests are ordered
  - Patients may not be aware test has been ordered

### **Health Literacy and Prostate Cancer**

- Experts suggest inclusion of
  - Uncertain value of screening
  - Possibility of false-positive and false-negative tests
  - Potential need for additional testing

### **Health Literacy and Prostate Cancer**

- Common situations
  - Patient does not know medical/technical terms for common body functions
  - Study findings
    - Less than 50% understood “erection” or “impotent”

### **Health Literacy and Prostate Cancer**

- Only 5% understood “incontinence” – most misunderstood word
- 2/3rd didn’t know “vaginal intercourse”
- Other unknown words: rectal urgency; urinary frequency, urinary function

### **Health Literacy and Prostate Cancer**

- Common situations
  - Patients do not know key anatomical structures or functions
    - Patients may have heard about prostate, but don’t know what it does

### **Health Literacy and Prostate Cancer**

- Patients frequently (1/3 in study) could not locate the bowels or bladder
- Patients don't know about prostate cancer – even among survivors

### **Health Literacy and Prostate Cancer**

- Literacy issues are important because they are used in
  - Informed consent documents
  - Quality of life measures
  - Patient education materials

### **Health Literacy and Prostate Cancer**

- Even if documents are read aloud, there is still a high probability that terminology related to impotence or incontinence would not be understood

### **Diagnosing Health Literacy Problems**

### **Hiding the Signs of Low Literacy**

- Patient strategies to hide illiteracy
  - “Forgot my glasses”
  - “I’ll read this when I get home”
  - Always brings a companion
  - Hands information to companion
  - Numbers written on bottle lids to indicate dosing

### **Detecting Low Health Literacy**

- Observe the language spoken in your waiting room
- Hand an instruction sheet to patient upside down
- Ask patient to demonstrate the instructions on the sheet
- Review any samples of the patient’s handwriting

## Testing for Low Reading Skills

- **REALM - Rapid Estimate of Adult Literacy in Medicine**
  - Doesn't test comprehension
  - Uses common layman's terms for body parts/illnesses
  - Takes 2-3 minutes to give and score
  - Uses three lists of 22 words each
    - Patient reads list aloud until 10 words are mispronounced

## Testing for Low Reading Skills

- **Sample**

List 1	
Fat	_____
Flu	_____
Pill	_____
Dose	_____
Eye	_____
Stress	_____

## Detective Methods that May Not Work

- Direct questioning may not reveal true answers
- Education level not necessarily an indicator
- General reading skills may not reflect health literacy skills

## Minimizing the Consequences

## What You Can Do

- Interventions can occur at two levels
  - Interpersonal – between you and your patient
  - Organizational – involving you as a leader among other health care professionals
- The quality of care you provide will be enhanced for ALL patients by following these guidelines

## Create A Shame-free Environment

- Create a shame-free environment where patients feel free to
  - Ask questions
  - Share information
  - State preferences



## **Create A Shame-free Environment**

- **Shame-free environment leads to**
  - **Improved health outcomes**
  - **Improved patient satisfaction**

## **Communication Techniques**

- **Practice active listening**
- **Use plain language**
- **Use the teach-back technique**
- **Reinforce message with appropriate materials**

### **1. Active Listening**

- **Active listening is not always “natural” for busy health professionals**
- **Use non-verbal signals while a patient talks**
  - **Smile at the patient**
  - **Make eye contact with the patient**

### **1. Active Listening**

- **Nod your head**
- **Take notes**
- **Stand or sit so that you and the patient are physically close and on the same “level”**

### **2. Use Plain Language**

- **Speak slowly and limit the amount of information given at one time**
- **A patient should leave the office knowing three things**
  - **What is the main problem?**
  - **What does he or she need to do?**
  - **Why is it important for him or her to do this?**

### **2. Use Plain Language**

- **Studies suggest that clinicians may have to use colloquial terms to effectively communicate with patients about prostate cancer treatment options**
- **The use of non-technical or plain language may seem especially difficult within a health care environment, but if your goal is to be understood, it is very important**

### **Examples of Plain Language**

- Reflects the needs of the patient rather than the legal, bureaucratic, or technological interests of the health care system
- Instead of
  - Referral
- Say
  - I ask you to see another doctor
  - Get a second opinion

### **Examples of Plain Language**

- Instead of
  - Procedure
- Say
  - Something done to treat your problem
  - Operation

### **Examples of Plain Language**

- Instead of
  - Generic
- Say
  - Product sold without a brand name like ibuprofen
  - Advil is a brand name

### **Examples of Plain Language**

- Instead of
  - Excessive
- Say
  - Too much
  - Example: (bleeding): if blood soaks through the bandage

### **3. Use 'Teach-Back' or 'Show-Me'**

- Check patients' understanding
- Asking is not enough
- Ask "tell me" questions
  - If you just ask, 'Do you understand?' -- people will say 'yes'
  - If you just ask 'Do you have any questions?' -- people will say 'no'

### **3. Use 'Teach-Back' or 'Show-Me'**

- Have patients demonstrate or "show" instructions
  - Example
    - "I just want to make sure when you get home you'll understand my instructions. Show me how you will take your medicine when you are at home."
- Don't put patient on the spot

#### **4. Use Supplements**

- To reinforce your message
  - Use simple props and visuals
    - Use familiar items/situations
    - Frame prostate within larger context of the body

#### **4. Use Supplements**

- Use culturally and linguistically appropriate materials
  - Be aware of cultural or other issues common to groups in your area

#### **Why Use Simple Props and Visuals?**

- To reduce amount of reading
  - Visuals can take the place of text
- To emphasize your instructions
  - Increases likelihood that patients will remember

#### **Why Use Simple Props and Visuals?**

- To motivate behavior change
  - Visuals boost retention when visuals are appealing and clearly relevant to patient

#### **Patient Friendly Materials**

- Beneficial to physician and patient
  - Consider re-working existing materials
  - Start with items most important to practice
  - Test with patients for greater effectiveness
  - Adapt other materials or find new items

#### **Creating Patient Friendly Materials**

- Keep content concise and focused
  - Focus on key points
  - Emphasize what the patient should do
  - Keep anatomy and physiology to the basics

### **Creating Patient Friendly Materials**

- **Tips for easy-to-read materials**
  - Simple words (1-2 syllables)
  - Short sentences (4-6 words)
  - Short paragraphs (2-3 sentences)
  - Use headings, bullets and lots of white space
  - Limit medical jargon (or define in plain language)

### **Verbal Comprehension Also Affected**

- **Patients only have 50% comprehension and recall of what they are told in the doctor's office**
- **Verbal instructions**
  - Keep it simple and easy to understand

### **Verbal Comprehension Also Affected**

- Patients want more information that will help them solve their problems
- **Written materials**
  - Reinforce verbal instructions
  - Simple and easy to understand

### **Verbal Comprehension Also Affected**

- Provide information that helps manage health problems – need more than background information on the disease itself

### **What About Readability?**

- **Readability ≠ comprehension**
  - SMOG “Simplified Measure of Gobbledygoop” formula is frequently used
  - FRY, other scales also available
- **Readability scores focus on the material**

### **What About Readability?**

- **Readability scores do not**
  - Indicate patient's understanding
  - Predict patient comprehension
  - Tell you how the material is perceived
    - Attractive, accurate, or applicable

## How You Can Help

## Patient Involvement

- Lead patients to self-manage health
- Actively promote patient involvement and shared decision making based on patient preference
- Invite family members or friends
- Refer to local literacy programs

## Use AskMe3

- Patients need to know the answers to
  - What is my main problem?
  - What do I need to do?
  - Why is it important for me to do this?

## Use AskMe3

- Free tools available at <http://www.npsf.org/askme3/>
  - Brochures
  - Implementation guide
  - Resources

## Family Support

- One on one interaction with patient is goal, may not always be possible
- The support of family and friends may be needed to negotiate health care system
- Especially true when chronic illness or severe disability is present

## Family Support

- Patients not required to use family for interpretation services – family members may also have low health literacy