## Globalization of Healthcare and Shared Decision Making







FOUNDATION FOR
INFORMED MEDICAL
DECISION MAKING

Hospital Authority Convention 2011

Michael J. Barry, MD

Foundation President

Professor of Medicine, Harvard Medical School



#### **Foundation Mission**

- Mission
  - The mission of the Foundation is to inform and amplify the patient's voice in health care decisions











#### **Foundation Principles**

Guiding Principles

We believe patients have the right to be:

- Supported and encouraged to participate in their health care decisions
- Fully informed with accurate, unbiased and understandable information
- Respected by having their goals and concerns honored









#### **Foundation Principles**

## We believe fully informed patients understand:

- There is seldom one right choice for everyone
- The full range of their options
- The risks and benefits of their options
- What may happen without any intervention
- When evidence is lacking
- Why their participation is important









#### The Foundation and Health Dialog

- The Foundation has a licensing agreement with Health Dialog
  - Provides royalties and contract funding to develop and maintain decision support materials
- Strict conflict-of-interest policy
  - Staff and Medical Editors are prohibited from financial support from the drug and device industries











#### Is Informed Consent "Real"?

- In a survey of consecutive patients scheduled for an elective coronary revascularization procedure at Yale New Haven Hospital in 1997-1998
  - 75% believed PCI would help prevent an MI
  - 71% believed PCI would help them live longer

(Holmboe ES. JGIM 2000; 15:632)









#### Is Informed Consent "Real"?

- While even through the latest meta-analysis in 2009 (61 trials, 25,388 patients):
  - "Sequential innovations in catheter-based treatment for nonacute coronary artery disease showed no evidence of an effect on death or myocardial infarction when compared to medical therapy."

(Trikalinos TA. Lancet 2009; 373:911)









#### Is Informed Consent "Real"?

- In a survey of consecutive patients consented for an elective coronary angiogram and possible percutaneous coronary intervention at Baystate Medical Center in 2007-2008
  - 88% believed PCI would help prevent an MI
  - 76% believed PCI would help them live longer

(Rothberg MB. Annals Intern Med 2010; 153:307)









#### **DECISIONS Survey**



- Conducted by University of Michigan
- Nationwide random-digit dial telephone survey
- Probability sample of 2575 English speaking Americans age 40<sup>+</sup>
- Response rate 51%









#### **DECISIONS Survey: Decisions Addressed**

- Surgery
  - Back surgery,
  - Knee/hip replacement
  - Cataract extraction
- Cancer screening
  - Prostate,
  - Colorectal
  - Breast
- Medications
  - Hypertension,
  - Hyperlipidemia,
  - **Depression**











#### **Epidemiology of Medical Decisions**

- In the past 2 years:
  - 56% discussed starting or stopping meds for hypertension, hyperlipidemia or depression
  - 72% discussed a screening test for cancer
  - I 6% discussed one of the 4 operations









#### Were Patients Asked for their Opinions?

#### For surgery:

- 80% the time for the orthopedic surgeries
- 65% of the time for cataracts

#### For screening:

20-35% of the time

#### · For medications:

- 50% of the time for cholesterol/blood pressure
- 75% of the time for depression medication

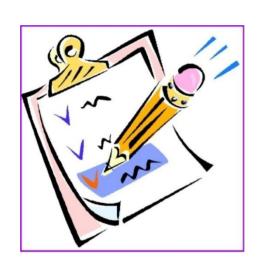








#### **How Much did Patients Know?**



- Clinical experts identified 4-5 facts a person should know, for example, common side effects of medications or surgery
- Respondents were asked the knowledge questions related to their decision
- For 8 out of 10 decisions, fewer than half of respondents could get more than one knowledge question right.

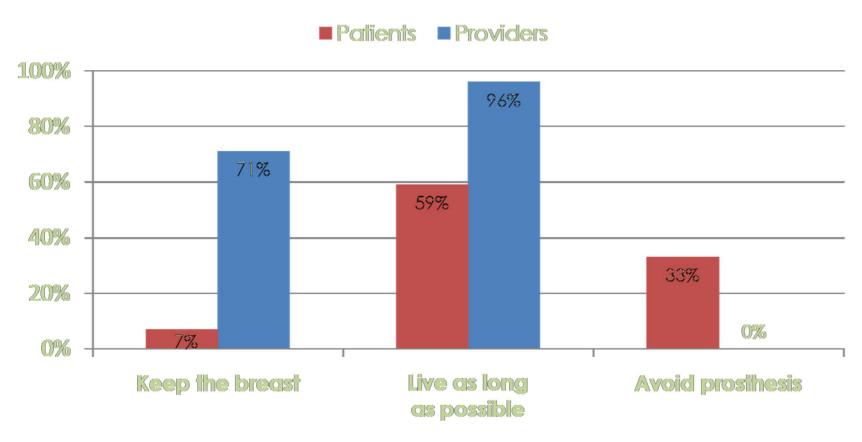








#### "Diagnosis" of Patient Preferences



(Lee CN, et al. Health Expect 2010 Sep 1;13(3):258-72. Epub 2010 Jun 9)









# Patients: Making Decisions in the Face of Avoidable Ignorance

# Clinicians: Poorly "Diagnosing" Patients' Preferences



## Poor Decision Quality Unwanted Practice Variation

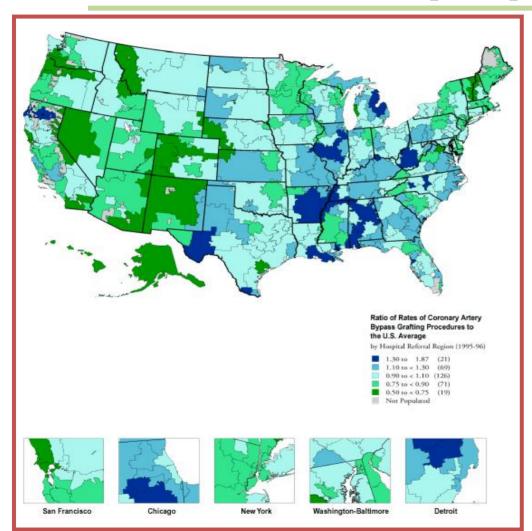


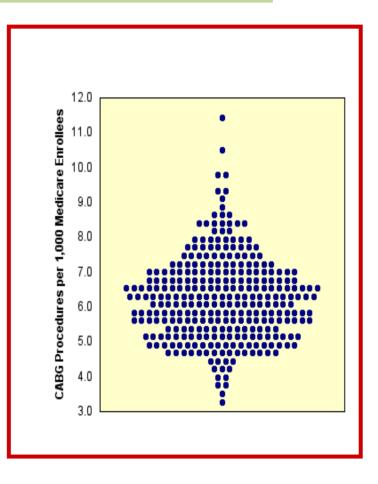






#### **U.S.** Coronary Bypass Rates









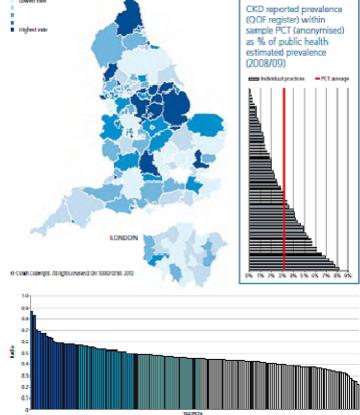




#### NHS Atlas of Variation in Healthcare



## Map 24: Ratio of reported to expected prevalence of chronic kidney disease (CKD) by PCT 2008/09 CKD reported prevalence (QOF register) within sample PCT (anonymised)











#### What is Good Medical Care?

- It is not just about doing things <u>right</u>
- It is also about doing the *right thing*
- Proven effective care: For some medical problems, there is one best way to proceed
- Preference-sensitive care: For many and perhaps most medical problems, there is more than one reasonable option









#### Patient Safety: A Bed versus B Bed Errors











#### **Shared Decision-Making Model**





- At least two participants –
   [clinician] and patient are involved
- Both parties share information
- Both parties take steps to build a consensus about the preferred treatment
- An agreement is reached on the treatment to implement

(Charles C, Soc Sci Med 1997; 44:681)









#### Patient Decision Aids Can Help!



- Tools designed to help people participate in decision making
- Provide information on the options
- Help patients clarify and communicate the values they associate with different features of the options.

(The International Patient Decision Aid Standards Collaboration)









#### Patient Decision Aids Can Help!

- Do not advise people to choose one option over another
- Not meant to replace practitioner consultation.
- Prepare patients to make informed, values-based decisions with their practitioner.







#### **Cochrane Review of Decision Aids**

 In 55 trials in 6 countries of 23 different pDAs, use has led to:



- -Greater knowledge
- -More accurate risk perceptions
- -Greater comfort with decisions
- -Greater participation in decision-making
- -Fewer people remaining undecided
- -Fewer patients choosing major surgery, PSA tests

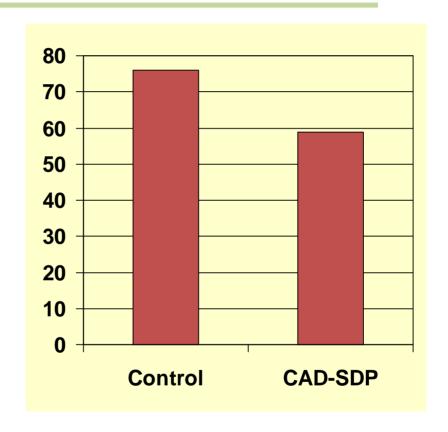
(O'Connor et al. Cochrane Database of Systematic Reviews 2009, Issue 3. Art. No.: CD001431)



#### Effect of pDA on Revascularization

- RCT among 240
   ambulatory patients in

   Toronto with CAD
- Usual care or CAD-pDA
- Revascularization chosen by 75% with usual care, 58% with CAD-SDP (p=0.01)
- Revascularization performed on 66% with usual care, 52% with CAD-SDP (p=0.06)



(Morgan et al. JGIM 2000; 15:685)









#### **IPDAS** Collaboration



(Elwyn et al. BMJ 2006;33:417)

- The IPDAS Collaboration has developed and published criteria for judging the quality of decision aids
- I22 people from I4 countries and 4 stakeholder groups participated
- Criteria are available as a checklist for users









Did the patient know a decision was being made?

Did the patient know the pros and cons of the treatment options?

Did the provider elicit the patient's preferences?

# **Decision Quality**

#### **Values Concordance**

Did the decision reflect the patient's goals and concerns?

#### Knowledge

Did the patient know what he or she needed to know?

(Sepucha KR, et al. Health Aff (Millwood). 2004; Suppl Web Exclusives:VAR54-62.)









#### The Greatest Untapped Resource in Health Care?

- In December 2010, 58 people from 18 countries attended a Salzburg Global Seminar to consider the role patients should play in healthcare decisions around the world
- They agreed a statement that calls on patients and clinicians to work together as co-producers of health



(http://www.salzburgglobal.org/current/sessions.cfm?nav=home&IDSPECIAL\_EVENT=2754)





























# The Salzburg Statement on Shared Decision Making

Clinicians and patients working together to be co-producers of health









We Call on Clinicians to:

 Recognise that they have an ethical imperative to share important decisions with patients

Stimulate a two-way flow of information and encourage patients to ask questions, explain their circumstances, and express their personal preferences









- We Call on Clinicians to:
  - Provide accurate information about options and the uncertainties, benefits and harms of treatment
  - Tailor information to individual patients needs and allow them sufficient time to consider their options
  - Acknowledge than most decisions do not have to be taken immediately, and give patients and their families the resources and help to reach decisions





- We Call on Clinicians,
   Researchers, Editors,
   Journalists, and Others to:
  - Ensure that the
    information they provide is
    clear, evidence-based, and
    up to date and that
    conflicts of interest are
    declared









We Call on Patients to:

 Speak up about their concerns, questions, and what's important to them

- Recognise that they have a right to be equal participants in their care
- Seek and use high-quality health information









- We Call on Policymakers to:
  - Adopt policies that encourage shared decision making, including its measurement, as a stimulus for improvement
  - Amend informed consent laws to support the development of skills and tools for shared decision making











#### **SDM: Implementation Needs**

- Patients interested in being informed and activated
- Practical protocols for routine use of decision support tools
- Health care systems with incentives for good "decision quality" rather than simply "more is better"
- Clinicians and hospitals receptive to patient participation











#### **Thank You!**

mbarry@fimdm.org

www.informedmedicaldecisions.org





