Globalization of Healthcare and Shared 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 non-acute 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+
- Reported a discussion of 1 of 9 medical decisions with a health care provider within the past 2 years
- Response rate 51%

(The Decisions Study. Medical Decision Making 2010; 30 supplement 1)
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
  – 16% 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

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

PROBLEMS OF THE GENITO-URINARY SYSTEM

Map 24: Ratio of reported to expected prevalence of chronic kidney disease (CKD) by PCT

Now available in InstantAtlas interactive version

The NHS Atlas of Variation in Healthcare
Reducing unwarranted variation to increase value and improve quality

Right Care

www.rightcare.nhs.uk
What is Good Medical Care?

• It is not just about doing things **right**
• 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

• Key characteristics:
  – 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

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.

(The International Patient Decision Aid Standards Collaboration)
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)
The IPDAS Collaboration has developed and published criteria for judging the quality of decision aids.

- 122 people from 14 countries and 4 stakeholder groups participated.
- Criteria are available as a checklist for users.

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

Did the patient know a decision was being made?
Did the patient know the pros and cons of the treatment options?
Did the patient know the patient’s goals and concerns?

Decision Quality

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

Values Concordance

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

Knowledge

Did the provider elicit the patient's preferences?

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

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.

Salzburg Global Seminar

(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
Salzburg Statement on SDM

• 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
Salzburg Statement on SDM

• 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
Salzburg Statement on SDM

• 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
Salzburg Statement on SDM

• 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
Salzburg Statement on SDM

• 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