Preparing Patients for an Active Role in Care

“Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care”

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National Coalition for Cancer Survivorship and Institute of Medicine National Cancer Policy Forum Workshop
February 28, 2010
PATIENTHOOD: What Patients are Asked to do NOW

- Choose a health plan, understand benefits
- Choose a physician/provider
- Provide concise histories
- Give “informed” consent
- Participate in some treatment decisions (rare)
- Follow-through on treatment plans
What Help Are Patients Given?

Very little....
‘Shared’ or Participatory Decision-Making: Definition

“The process of negotiation by which physicians and patients arrive at a specific course of action, based on a common understanding of the goals of treatment, the risks and benefits of the chosen course vs. reasonable alternatives, and each other’s values and preferences”
Background

• There is currently no systematic training or preparation for being a patient in the US

• Average patient asks fewer than 4 questions in a 15 minute office visit
Background (cont’d)

• Most patients don’t participate effectively in treatment decisions
• Traditional patient education improves knowledge but not other outcomes
Prevailing Myths…

• Patients are too poorly educated to participate in care
• Patients don’t want to participate
• Patient participation will lengthen visits
• Encouraging patients to participate will make them ‘difficult’ patients
WHY TRAIN PATIENTS TO PARTICIPATE IN CARE?
Patient vs. Physician ‘Effects’: HbA1c levels
SHOULD PATIENTS BE PASSIVE?
Empirical Results
Evidence

- Majority of patients (study range: 60% - 90%) say they prefer either active or shared/collaborative role in decisions
- Physicians substantially underestimate patients’ interest in active role
- Passive patients have poorer health outcomes
Characteristics Associated with Less Effective Patient Skills

- Older (>60) patients
- Men
- Less educated (<high school)
- More passive
- Minorities
TRAINING PATIENTS TO PARTICIPATE IN MEDICAL CARE
Features of Coached Care

- Algorithm mapping decisions, treatment options; detailed explanations
- Patient’s medical record; tailored information
- Reviewed immediately before office visit
- ‘Coaching’ for more effective participation during visit
Coached Care Studies

• Diseases studied: diabetes mellitus (x2), hypertension, peptic ulcers, breast cancer, rheumatoid arthritis

• Sites: University teaching hospital clinics, private practices, outpatient clinics

• Patients: middle-aged, average education; most recently poor, minorities
RESULTS FROM THE COACHED CARE PROGRAM: Health Outcomes

• Compared to controls, patients in experimental group had:
  – Improved glycemic control
  – 25% reduction in symptoms
  – 30% improvement in functional status
RESULTS FROM THE COACHED CARE PROGRAM: Communication

- Compared to controls, patients in experimental group:
  - 3 times more questions, ‘controlling’ conversational behaviors
  - 2 times more effective in information seeking
Patients’ Evolving Role in Care: The Case for “Planned Patienthood”

- Links with improved health outcomes:
  - Participatory decision making; shared decision making
  - Effective doctor-patient communication
  - Less passive approach to healthcare
  - Interventions to improve patient participation in treatment (e.g. Coached Care)
Training Advanced Patienthood...
What Doctors Wish Their Patients Knew

Best Buy drugs (And where to get them for $4 a month)
How to find Dr. Right
Effective Patient Skills

- Ask focused questions
- Understand options exist; elicit options
- Understand risks and benefits of treatment options
- State personal preferences, relevant life circumstances affecting treatment options
- Understand physician’s preferences
- Negotiate conflicts
- Participate in formulation of ‘personalized’ treatment plan
Barriers in Using Risk-Benefit for Better Treatment Decisions

- Patients’ inability to understand quantitative information (innumeracy);
- Patient assumptions about benefit and risk (for example, automatically associating high benefit with low risk);
- Whether or not the prescribing physician has voiced his or her opinion;
- How information on drug benefits and risks is presented to the patient;
- Nature of the patient’s condition; and
- Patients’ tolerance of uncertainty.
### Everyday risks

- Death in one year
- Death from smoking 10 cigarettes a day for one year
- Death—all causes to age 40
- Death in road traffic crash in one year
- Death by accident at home
- Death by accident at work
- Death by murder in one year
- Death in rail crash
- Death by lightning strike or nuclear power accident
- Six balls in UK National Lottery

### Clinical risks

- Very high: 1 in 100
- High: 1 in 1000
- Moderate: 1 in 10,000
- Low: 1 in 100,000
- Very low: 1 in 1,000,000
- Minimal: 1 in 10,000,000
- Negligible: 1 in 100,000,000

- Neurological injury with spinal damage
- Neurological injury with epidural
- Anaesthetic awareness
- Death from anaesthesia CEPOD 1982
- Spinal haematoma after epidural
- Death from anaesthesia CEPOD 1987
- Spinal haematoma after spinal damage
- Maternal deaths from anaesthesia CEMD 1988-90
- Death from variant Creutzfeldt-Jakob disease
Who Should Train Patients?

• Parents
• School health nurses
• Pediatricians
• Physicians
• Other providers (nurses, nurse educators)
• Other health personnel (e.g. coaches, navigators)
• Health systems, hospitals
• Web
Who Should Pay for Training Effective Patients
Toward Advance Patienthood: Where Next?

- Training programs may need to begin in childhood?
- Use advanced technology (Internet, cable TV, closed circuit TV, software) to provide training in remote settings?
- Specifically target subgroups in need of more help to participate effectively (e.g. males, elderly)?