Promises and Challenges of Shared Decision Making in Practice

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The Promise

Comprehensive Medical Information

Patients Informed Preferences
The Promise

“The DECISION”

Comprehensive Medical Information

Patients Informed Preferences
The Reality

- Select “Decisions” from recent Wednesday Clinic (5 out of 20 patients)

  87 yo woman with new breast & axillary mass found on screening mammogram. Should she pursue surgery, neoadjuvant endocrine therapy, nothing?

  45 yo woman with stage IV disease progressing on 4th line chemotherapy. Should we pursue next line of chemotherapy, return to endocrine Rx, consider clinical trial, or stop disease directed Rx and pursue palliative care alone?

  52 yo woman with Stage II disease, hospitalized for hypotension and shortness of breath following last cycle of adjuvant chemo, work-up unrevealing, now better and in clinic for consideration of cycle #3. Continue? Move to endocrine therapy? Change chemotherapy?

  37 yo woman with newly diagnosed node negative, ER + disease, should we pursue adjuvant chemotherapy in addition to endocrine Rx? How should her desire to have an additional child factor in to this decision?

  59 yo woman with newly diagnosed node + ER+ breast cancer s/p lumpectomy who is opposed to any “unnatural” interventions. Should she do radiation therapy, chemotherapy, & endocrine therapy or alternative herbal therapy?
The Promise and the Reality
Why is this Important?

- Respect for Autonomy
- Life/Death
- Morbidity/Symptoms
- Costs/Trade-offs (time, $, work, family)
- Satisfaction with care, decisions, outcomes
- Adherence (?)
Reality:
37 yo woman with newly diagnosed node negative, ER + disease

Chemotherapy
Prediction Assay?
Which Regimen?
Clinical Trial?
Regimen Details?
Common toxicity?
Rare Toxicity?
Long term toxicity?
Fertility Impact?
Fertility Options?
Social Impact?
Employment Impact?
Financial Impact?

Benefit from Therapy
Toxicity
• Side Effects
• Rare risks

Prognosis?

Decision

Endocrine Rx
Which drug?
Ovarian Suppression?
Clinical Trial?
Common toxicity?
Rare Toxicity?
Long term toxicity?
Fertility Impact?
Duration of Therapy?
Social Impact?
Employment Impact?
Financial Impact?
How are we doing?

Detailed Discussions

Variable Discussion

Local Therapy for Prostate Cancer

Adjuvant Breast Cancer

Palliative Care Discussions

4th Line Breast Cancer

Advanced Lung Cancer

Pancreatic Cancer
45 yo woman with stage IV disease progressing on 4\textsuperscript{th} line chemotherapy.

- Analogous to many cancers after 1\textsuperscript{st} or 2\textsuperscript{nd} line therapy

- Options include:
  - Further disease directed therapy
  - Palliative care alone or in combination with above
  - Clinical trial (Phase I, II, III)
ASCO Statement on Individualized Care For Advanced Cancer

• “When cancer directed therapy is considered, the patient must be told:”
  – The likelihood of response
  – The nature of response (i.e. symptom improvement, shrinking tumors, slowing progression, improving survival)
  – Toxicities to which they will be exposed
  – Provision of both pessimistic information (the chance of no response) and optimistic information (chance of response)
  – Direct financial impact of treatment decisions
  – Costs in terms of time, toxicity, and alternatives that will be precluded by a given treatment decision

Peppercorn et al, JCO 2011
Challenges

- Information
- Assessment (Time and Skill)
- Decision Making Process
- Clinical Constraints on Decisions
- Structural Constraints on Decisions
- Patient/Family Conflict
- Patient/Doctor Conflict
Broad Questions for Shared Decision Making

• How much information?

• What range of options?

• (How) do we address MD influence?
Optimal Context for Shared Decision Making?

“I’m going to take your blood pressure, so try to relax and not think about what a high reading might mean for your chances of living a long, healthy life.”
“All these years, and you haven’t listened to a damn thing I’ve said, have you?”
Challenges: Off-Protocol Therapy

• Example: 47 yo woman diagnosed with multinode + breast cancer, high risk for recurrence.
  – She is eligible for a randomized trial of a promising new drug, approved several years ago for metastatic breast cancer.
  – The drug is FDA approved and commercially available, but not proven in this setting.
  – The patient reviews the trial consent form, reads some information on line about the drug, and decides that she want to be treated with the experimental drug outside of the clinical trial, in part to guarantee that she is not randomized to standard of care alone....

• What Should The Doctor Do?
Focus Group Responses to Off-Protocol Therapy

Access, Benefit

Research, Safety
Challenge: “Bad” Decisions

• Example: A 32 year old woman is diagnosed with node positive “triple negative” breast cancer
• She undergoes neoadjuvant therapy with an excellent clinical response.
• She decides that she does not want surgery, and finds an alternative practitioner who suggests that herbal manipulation of her immune system may be enough to keep the disease in check....

• What should the doctor do?
• What if she requests biannual breast MRI to monitor for recurrence? (data free zone...)
Therapeutic Options

- Potential Conflict
- Evidence of Harm
- Clear Evidence of Benefit
- No Evidence of Benefit
- No Intervention
- Possible Benefit

Depends
Core Competencies...

• Knowledge of the field
  – Can’t explain prognosis, options, and potential consequences if you don’t know them yourself

• Ability to Translate
  – Across Educational level, cultural context, age, gender, and other individual differences

• Empathy
  – Need to know why this is important, and to care.

• Efficiency
Steering Between Paternalism and Healthcare as “IHOP Menu”
Promise

• Medical Decisions will remain complex

• Decisions can better reflect patient goals and preferences
  – Informed by: prognosis, evidence based options
  – Requires Empowering Patients and Educating Physicians

Need to Identify Priority Areas and “Best Practices”
  – Content and Nature of Discussions and Decisions must be tailored to the individual patient and the specific clinical setting
Questions for Discussion

• How can patient preferences be assessed in the context of medical decision making?

• Are patient preferences usually taken into account?

• What is the role of a patient when discussing a treatment plan? What is the role of the care team?

• What are the barriers to incorporating patient preferences and shared decision making in cancer treatment planning?