Understanding and Utilizing Patient Preferences in Cancer Treatment Decisions

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A Choice: Prostate Cancer Treatment Options

Surveillance

Active Treatment

Surgery

Radiation

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Active treatment **MAY increase life expectancy for men with long life expectancy (young) and Gleason 7 cancer**
The “Right” Choice

<table>
<thead>
<tr>
<th></th>
<th>Active Surveillance</th>
<th>Active Treatment</th>
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</thead>
<tbody>
<tr>
<td>Medical</td>
<td></td>
<td></td>
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<tr>
<td>Cancer severity</td>
<td>Low (Gleason 6)</td>
<td>Intermediate (Gleason 7)</td>
</tr>
<tr>
<td>Life expectancy</td>
<td>Shorter (older)</td>
<td>Longer (younger)</td>
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<tr>
<td>Personal Preferences</td>
<td></td>
<td></td>
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<tr>
<td>Interest in sex</td>
<td>Higher</td>
<td>Lower</td>
</tr>
<tr>
<td>Anxiety about prostate cancer</td>
<td>Lower</td>
<td>Higher</td>
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The “Right” Choice

- Depends on how patient weighs trade-off between
  - Anxiety of living with cancer
  - Side effects of “active treatments”
    - Surgery
    - Radiation
My Questions

- How well do doctors share
  - In shared decision making?
- What does autonomy look like today
  - In the doctor’s office?

A Study of Prostate Cancer Decision Making
Recruitment & Randomization

- Patients approached at their biopsy appointment
- Asked to participate in a study about prostate cancer treatment decision making.

Key Measures

- Patient Preferences
  - What treatments were they considering
    - Prior to urology appointment
    - After reviewing a decision aid
- Decision of relevant values
  - e.g. How interested in sexual function
- Physician discussion of pros/cons
- Physician Recommendations
  - Against: “Surgery is not an option for you.”
  - For: “At your age, surgery is the best treatment.”
Results
Delivering the Diagnosis

- “So we took twelve cores out of your prostate.
- Out of those there were three cores that had cancer in them, and the percentage of the cores that was cancer was fairly low, it was under 30%.
- So out of those three cores, that are about, you know, this long, a third of them had a little bit of cancer in them.
- So those three cores out of twelve says that there’s probably not an extensive amount of prostate cancer in your prostate.
- But we should talk about different treatment options.”

A Research Meeting

- Discussed how urologists broke bad news
  - And had a vehement disagreement
- My view
  - People need TIME to recover from bad news
  - Before making complex decision
But Instead of Time, Got More Info

- “Yep, so 6 is what we consider the most low-grade, least aggressive looking, but it’s the most…it’s just abnormal enough for us to call it cancer.
- If it were any less than that, if there were less atypical looking cells, we couldn’t call it cancer.
- So it’s just enough to get a grade of cancer.
- And then that goes all the way up to a score of 10 which is very abnormal looking and is more aggressive.”

Some Fuzzy Math

- “Low risk is Gleason 6, intermediate is usually 7’s, either 3+4 or 4+3, depending on how it looks under the microscope.
- And then 8, 9 and 10 are all high risk.
- So yours was an intermediate risk.
- So it’s in the middle.
- It was 3+3 and 3+4, so just enough of the atypical cells of the grade 4 to make it 3+4, which means you’re intermediate risk.”
Result of Information Overload

- People can be harmed by receiving too much information
- Overload reduces
  - Comprehension
  - Retention
- And even has surprising effects on choice

Too Many Choices?

- Supermarket testing booth
- A specialty jam company’s products were chosen
  - because they had lots of jams
- Grocery stores randomized so that
  - 6 jams were displayed
  - 24 jams were displayed

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Outcomes

- Which booth was visited most often?
  - 24 jams
- Which booth did more people taste jam at?
  - 24 jam booth
- Which booth led to more jam sales?
  - 6 jam booth

YIKES!

First Problem with Shared Decision Making

- Thorough communication
  - Not always good communication
- Good communication takes
  - Time
    - To acknowledge and deal with emotion
    - To absorb and reflect on information
  - Ability to take patient’s perspective
    - e.g. Jargon
How well did discussions promote “autonomous” decision making?

### Changing Preferences

<table>
<thead>
<tr>
<th>Treatment Preference Prior to Appointment</th>
<th>N</th>
<th>Percent Receiving Active Treatment</th>
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</thead>
<tbody>
<tr>
<td>Only Surveillance*</td>
<td>44</td>
<td>55%</td>
</tr>
<tr>
<td>No preference for Surveillance versus Active Treatment</td>
<td>119</td>
<td>46%</td>
</tr>
<tr>
<td>Only Active Treatment ◊</td>
<td>118</td>
<td>54%</td>
</tr>
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</table>
What Came First...

- Patient preferences or physician recommendations?
- According to my urologic collaborators
  - “We know which way patients are leaning, and then make corresponding recommendations.”
- Question:
  - Did urologists elicit preferences
  - And then make recommendations?
**Discussion of decision-relevant preferences**

<table>
<thead>
<tr>
<th>Topic Area</th>
<th>% of Encounters</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Assessment of baseline erectile function and sexual activity</td>
<td>67%</td>
<td>Dr: How are your erections right now? Pt: Hmm, that’s not, so-so Dr: Are you sexually active? Pt: A little bit I don’t know</td>
</tr>
<tr>
<td>Assessment of importance patient places on sexual function</td>
<td>12%</td>
<td>Dr: So it seems like right now your biggest concern is your erectile function. Is that…? Pt: I mean, I mean, yeah!</td>
</tr>
<tr>
<td>Communication that sexual function preferences play a role in the treatment decision</td>
<td>13%</td>
<td>Dr: So your erections, when we do either treatment are going to take a hit, they’re going to be worse than they are now. Whether or not that is a bother for you, is something that only you can decide.</td>
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**What Do Recommendations Look Like?**
People [like you] who have a lot of tissue around their abdomen, [that] makes it dangerous to do surgery

You’re a Gleason 7. So what does that mean? It means that we shouldn’t just sit tight on this because it can cause problems later on in life

The fact of the matter is you had a few biopsies that were positive, and most people would advocate for you and say that you should do something about it rather than just watching it, although that still is an option for you

Most people, given your young age, will probably not recommend the radiation therapy. However, if you want to hear more about it, I am more than happy to ask for a counseling session with the radiation guys
Leaning Towards an Option

- We'll have you see the radiation doctors, but with sort of the low risk cancer and with the lung issues and stuff, watching it might be the best thing.
- So [radiation and surgery] are your two options...you're a bigger guy and so to get to your prostate [with surgery] will be more difficult. Not to say it’s impossible.

Saying What is Best Option

- We’re going to watch you carefully, but we’re not going to actually treat you per se for the cancer. That would be my opinion.
- My bias is that for somebody young and healthy, that I think would tolerate the surgery, and that I think would be around to experience some of those late side effects of radiation, I’d recommend surgery.
Recommendations Often Evolve

Opening Neutrality

- You have every option available to you in terms of how you want to proceed and my job now is to tell you what your options are and give you information.
- Every option has its risks; every option has its benefits.
Surveillance: Not so good

- You’re not a perfect candidate for active surveillance, meaning we’re a little bit more concerned about your disease.
- The people who we like to put on active surveillance are the people who we don’t think are going to progress in their cancer.

Neutral Between Surgery and Radiation

- I think that in terms of cure, [surgery and radiation] are roughly equivalent, they’re different techniques, so it’s hard to compare one to another and they’ve never been compared directly head to head.
But..Surgery is Better

- I’m a biased person…the reason I like surgery in a younger person [like you] is that no matter what you try, there’s risk that both therapies will fail at some point in the future...
- If we fail after surgery, we can radiate you. If you fail after radiation, we have fewer options.
- You can’t operate after radiation, that’s why I tend to reserve radiation for older people

Recommendations Often On Request
What Should I Do, DOC?

- Cannot blame physicians for giving recommendations
  - Have experience, expertise
  - Not overwhelmed by decision–relevant information

- And of course
  - Patients sometimes request recommendations!

The Language of Requests: Generic

- "What in your opinion would be best?"

- "What is your suggestion doctor?"

- "Excuse me, what do you prefer?"

- "What is your recommendation, and then I'll tell you mine."
The Language of Requests: Appeals to Experience

- "Because you're the surgeon, you know more about treatment..."
- "You're a Doctor, so judging from the situation right now..."

The Language of Requests: What Should I Do?

- "Which one should I have?"
- "At my age, what would you think?"
- Companion: "What would you suggest he do?"
The Language of Requests: If It Was You

› "What would you recommend if it was you?"

› "What would you do if you were sitting here in this chair?"

› "You're not me, but if you were me, what would you do?"

The Language of Requests: If It Was Your Dad

› "What would you do if it was your father?"

› "Your father comes to you, what would you do?"
Patients Give Doctors Permission to Make Recommendation

- "I'd ask for your personal opinion, but you probably can't give it."
  - "I think we can hardly pick a better candidate for surgery."
- "I know you can't give me an absolute answer here. So I'm going to ask you what you would do if you were sitting here in this chair."
  - "I don't know what the right answer is. I would strongly consider active surveillance."

Why This Language Matters

When what I would do is different than what I'd recommend that YOU do
You catch the eye of an attractive stranger

Your FRIEND catches the eye . . .
Imagine you have colon cancer

Surgery A
- 80% cure without complications
- 16% die of disease
- 1% colostomy
- 1% intermittent bowel obstruction
- 1% wound infection
- 1% diarrhea

Surgery B
- 80% cure without complications
- 20% die

Which surgery would you choose?

What would your doctor do?

What I did:
- Mailed survey to primary care physicians in US
- 40% chose surgery with
  - Higher death rate

Ran experiment at same time
- Half of docs asked to make Rx rec
  - Only 25% recommend that Rx
Another Problem: Physician Bias

- Previous research: Desire for surgery
  - Urologists > radiation oncologists
  - People like what they know

- How to deal with that?
  - One approach = Disclosure
  - e.g. “I’m a surgeon, so I’m biased in favor of surgery.”
Disclosure Backfires

- 26 patients heard explicit admission of bias
  - Those patients: MORE likely to have surgery
  - Even AFTER accounting for
    - Age
    - Tumor grade
    - And physician recommendation!

Lab Experiment

- Video of “doctor” describing surgery
  - Paraphrased from actual encounter
- ½ of people
  - Doctor admits bias
- Those peeps
  - Thought doctor more biased
    - Duh!
  - Trusted doctor more!
    - p = .02
  - More likely to recommend doctor to a friend
    - P = .01
Step 1: Teach Back

- Don’t assume patients understand decision-relevant information
  - Ask them to think out loud
- “I've given you lots of information and want to make sure I did a good job. Can you tell me in your own words what you heard me say?”
- Can be done at beginning of visit
  - “What do you know about your alternatives?”
Diagnose Patient Preferences

- When experts say that some patients do not want to partner in decisions
  - They really don't understand partnership

- At a minimum, patients need to help physicians understand their preferences

- "I'm the expert on the medical facts, but you're the expert on you."

- "What sounds good and bad to you about that treatment alternative?"

Understand, Before Recommending

- Don't make a treatment recommendation
- Until you understand your patient well enough to make a preference–relevant recommendation
Preference–based Recommendation

- Pt: "What would you recommend?"
- Dr: "So, surgeons will say surgery.... But I think it really is a personal decision that you have to make. Are you the kind of person where the idea of just watching your PSA is that unsettling to you?"
- Pt: "Yeah, I think I would."
- Dr: "Then I don't think you'd be a good candidate for the surveillance."

Finalizing the Patient Empowerment Revolution

The work of ethics

- Is undermined by
  - Poor communication
  - Naïve psychology
  - Failure to distinguish
    - Medical facts from
    - Value judgments
Who are “we” AKA Collaborators

- Angela Fagerlin
- Karen Scherr
- Tim Hofer
- Laura Scherer
- Margaret Holmes-Rovner
- David Rovner
- Kirsten Greene
- Valerie Kahn
- Jeff Montgomery
- Sunita Sah

- James Tulsky
- Stewart Alexander
- Sara Knight
- Bruce Ling

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"There cannot be many physicians who also do serious psychological research and explore ethical dilemmas of their profession. It is unlikely that there is anyone besides [name] who can do all these things so well."

—DANIEL KAHNEMAN, author of Thinking, Fast and Slow

CRITICAL DECISIONS
How You and Your Doctor Can Make the Right Medical Choices Together

PETER A. UBEL, M.D.