Personal Patient Profile - Prostate (P3P): Applying what matters most

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Localized Prostate Cancer: The Ultimate Treatment Decision

- Today, versus 20 years ago, we know a bit more to say when our patients ask, “but doctor, which treatment works the best?”
- We still reply with many “ifs” and “caveats.”
Treatment Decision Making in Men with Prostate Cancer

R29 CA 77372
1998-2003
The Decision Process – Individual Interviews

1. Talk with Urologist
2. Talk with friends &/or family &/or other men with prostate cancer
3. Read Books, Internet, magazines
4. Talk with one or more MD specialist
Qualitative Results

- **Core decision-making process:** “Making the best choice for someone like me”
- Men are compelled to place the diagnosis and all the potential outcomes in the context of their own lives.
  - What prostate cancer or other cancer has meant to them in the past
  - ‘Who I am’ and ‘what I do’ determines perspective
  - Guidance sought from others who have some similar contexts
  - Force MD to step into their contexts with the question, ‘what would you do if you were me?’
Conclusions

- Overall, this mixed methods study suggested that accurate information communicated to patients is of primary importance, not only for satisfaction with decision making but also for the actual treatment choice.

- Patient-reported factors are at play in the treatment decision and associated outcomes
  - Self-appraisal/personal priorities
  - Anxiety
  - Intimate relationships
  - Shared decision control (MD influence)
  - Use of the Internet
Decisional Needs

Uncertainty related to lack of medical evidence for best treatment strategy
Uncertainty related to potential adverse outcomes
Knowledge
Expectations
Personal factors
Clinical factors
Resources

High Quality Decision

Informed
Based on personal values and preferences
Timely & effective
Minimal regret
Appropriate use of resources

Clarify needs & personal factors
Provide medical facts
Customized coaching for communication

Figure 1. Adapted Ottawa Decision Support Framework
• How could we facilitate the patient-report of personal factors and also educate on medical factors tailored to men’s priorities?

• Could we make available any time, anywhere as preparation for decision making?
“Let me tell you what you need to know”
“Let me set you up with some information”
P3P: What it is and what it does

- Interactive Web-based decision support system in English and Spanish that works on all devices
- Synthesizes medical facts with patient factors (beliefs, preferences, concerns)
- Multi-media education and coaching based on patient priorities
- Prepares a man for the *options consultation* with the clinician and decision
Welcome to P3P

Personal Patient Profile - Prostate

Helping you make decisions about prostate cancer

I am a man with prostate cancer  I am a clinician

UNIVERSITY OF WASHINGTON

Learn more about P3P

P3P is for

Patients

Clinicians

By providing cancer care options that allow patients to share their values, preferences, and choices with the clinician.
Components of the Intervention

- Taking part in the treatment decision
  - Driven by Decisional Control Scale
- Understanding statistics-text and graphic
  - Driven by most influential outcome
- Top information topics – text/print-out
  - Driven by Information Priorities
Components of the Intervention

- **Influential people: text and video**
  - Driven by most influential person

- **Influential outcomes: text and video**
  - Driven by most influential outcomes

- **Current symptoms: text and video**
  - Driven by EPIC

- **Other informational web sites: text and printout**
Results: A total of 494 eligible men were randomized (266 intervention; 228 control). The intervention reduced adjusted decisional conflict over time compared with the control group, for the uncertainty score (estimate \(-3.61\); confidence interval, \(-7.01, 0.22\)), and values clarity (estimate \(-3.57\); confidence interval \((-5.85, -1.30)\)). Borderline effect was seen for the total decisional conflict score (estimate \(-1.75\); confidence interval \((-3.61, 0.11)\)). Time-to-treatment was comparable between groups, while undecided men in the intervention group chose brachytherapy more often than in the control group. Acceptability and usefulness were highly rated.
Competitive renewal

- Hybrid Type 1 effectiveness-implementation trial
  - A study in which a clinical intervention is tested while gathering information delivery and implementation in a real-world environment.
  - P3P met suggested criteria
    - low-risk intervention with face validity
    - evidence of efficacy in a different, but related, population.
My Top Concerns

Based on your answers, we’ve calculated which factors are most important to you. Start with the one below and use the links on the left to explore other areas.

Years I Expect to Live

Based on your answers, how long you expect to live (this is also called survival) is important to you as you decide on your prostate cancer care.

Age and other things that affect survival

Nearly all men with localized prostate cancer will live at least 10 years after their diagnosis. They may die sooner for another reason, like accidents or other illnesses. In general, prostate cancer is a slow-growing cancer.

For men with a low risk of cancer spreading or returning, there is no proof that any one kind of care will help them live longer than another kind of care. For men with a medium- to high-risk cancer, studies show that removing or treating the cancer is better than only watching it.

The most important thing in the risk of your cancer growing or spreading is the Gleason score of your cancer. There is good research that says that this score will predict how soon a man’s cancer will spread and how many years he will live. Your doctor will talk to you about your Gleason Score and risk of your cancer spreading or returning.

The way you feel about your own age now and how long you expect to live is important in choosing your prostate cancer care. Other diseases or illnesses you have, or that your family has, also can affect how long you expect to live.

TALK TO YOUR DOCTOR

Talk to your doctor about your age and how long you expect to live. For example, you might say:

“Doctor, I feel like a young man at (say your age) and like I’ve got plenty of years ahead of me. How long do you think I’ll live?”

Your doctor may say, “I don’t know. You’re young and healthy, but we’ll have to watch your prostate.”
Donna Berry

**Current decision status on options:**
I haven’t started to think about the options, but I want to start.

**Decision Control Preference:**
‘I prefer that my doctor(s) and I share the decision about which option is best.’

### Expanded Prostate Cancer Index Composite Short Form (Past 4 weeks)

<table>
<thead>
<tr>
<th>Domain</th>
<th>0 — Worse</th>
<th>Better → 100</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Urinary Incontinence</strong></td>
<td>29</td>
<td>63</td>
</tr>
<tr>
<td><strong>Urinary Irritation</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**EPIC Domains**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urinary Incontinence</td>
<td>29</td>
</tr>
<tr>
<td>Frequency</td>
<td>More than once a week</td>
</tr>
<tr>
<td>Dribbling</td>
<td>Frequent dribbling</td>
</tr>
<tr>
<td>Pad use</td>
<td>2 pads per day</td>
</tr>
<tr>
<td>Leaking</td>
<td>Big Problem</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urinary Irritation/Obstruction</td>
<td></td>
</tr>
<tr>
<td>Pain/burning</td>
<td>No problem</td>
</tr>
<tr>
<td>Bleeding</td>
<td>No problem</td>
</tr>
<tr>
<td>Stream</td>
<td>Small Problem</td>
</tr>
<tr>
<td>Frequency</td>
<td>Big Problem</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel</td>
<td></td>
</tr>
<tr>
<td>Urgency</td>
<td>No problem</td>
</tr>
<tr>
<td>Frequency</td>
<td>No problem</td>
</tr>
<tr>
<td>Control</td>
<td>No problem</td>
</tr>
<tr>
<td>Blood</td>
<td>No problem</td>
</tr>
<tr>
<td>Abd/pelvic/rectal pain</td>
<td>No problem</td>
</tr>
<tr>
<td>Overall bowel</td>
<td>No problem</td>
</tr>
</tbody>
</table>

**Sexual Interest, Activity and Satisfaction (Past 4 weeks)**

<table>
<thead>
<tr>
<th>Interest level</th>
<th>Quite a bit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity level</td>
<td>4 or more times</td>
</tr>
</tbody>
</table>

**Use of erectile aids:**
4 or more times

**Erectile aids:**
Pills, Penile Injection, Vacuum Erection Device, Other: Fancy machine
RCT-2013 to 2016

- Sites in Boston, MA, Atlanta, GA, Charlottesville, VA & southern California.
- 392 men were randomized (198 intervention; 194 usual care) and 305 men returned 1-month outcomes (152;153).
  - Diverse sample with regard to race, income and education
- The adjusted, multivariable model revealed significantly reduced conflict in the intervention group (-5.00 [-9.40, -0.59]).
- Other predictors of conflict included income, marital/partner status, decision status, number of consults, clinical site and D’Amico risk classification.

Berry et al., 2018
Patient-reported influential factors: Pooled responses from both RCTs
Odds of endorsing a factor

- Age
- Bladder
- Bowel
- Co-worker
- Conf.in. Doc
- Family
- FamousPersonPC
- Friend
- Religion
- Sex
- Spouse
- ToRecreat
- ToWork
- YearsToLive

Minority Group
- Black vs. White
- Hispanic vs. black
- Hispanic vs. white

Odds ratio & 95% CI
Summary

- In a preference-sensitive decision scenario, an assessment of patient-reported priorities provides opportunity for tailored intervention.
- A tailored intervention reduces patient-reported conflict associated with the decision.
- Personal priorities vary based on race/ethnicity in the US, further underscoring the need for customization.
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