



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

Qualitative:
Patients

Qualitative:
MD's

Quantitative

Pilot
Intervention

The Decision Process – Individual Interviews

13

Talk

With one or more MD specialist

25
25

Read-

Books, Internet, magazines

26

Talk

With friends &/or family &/or other men with prostate cancer

31
31

Talk with Urologist

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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

High Quality Decision

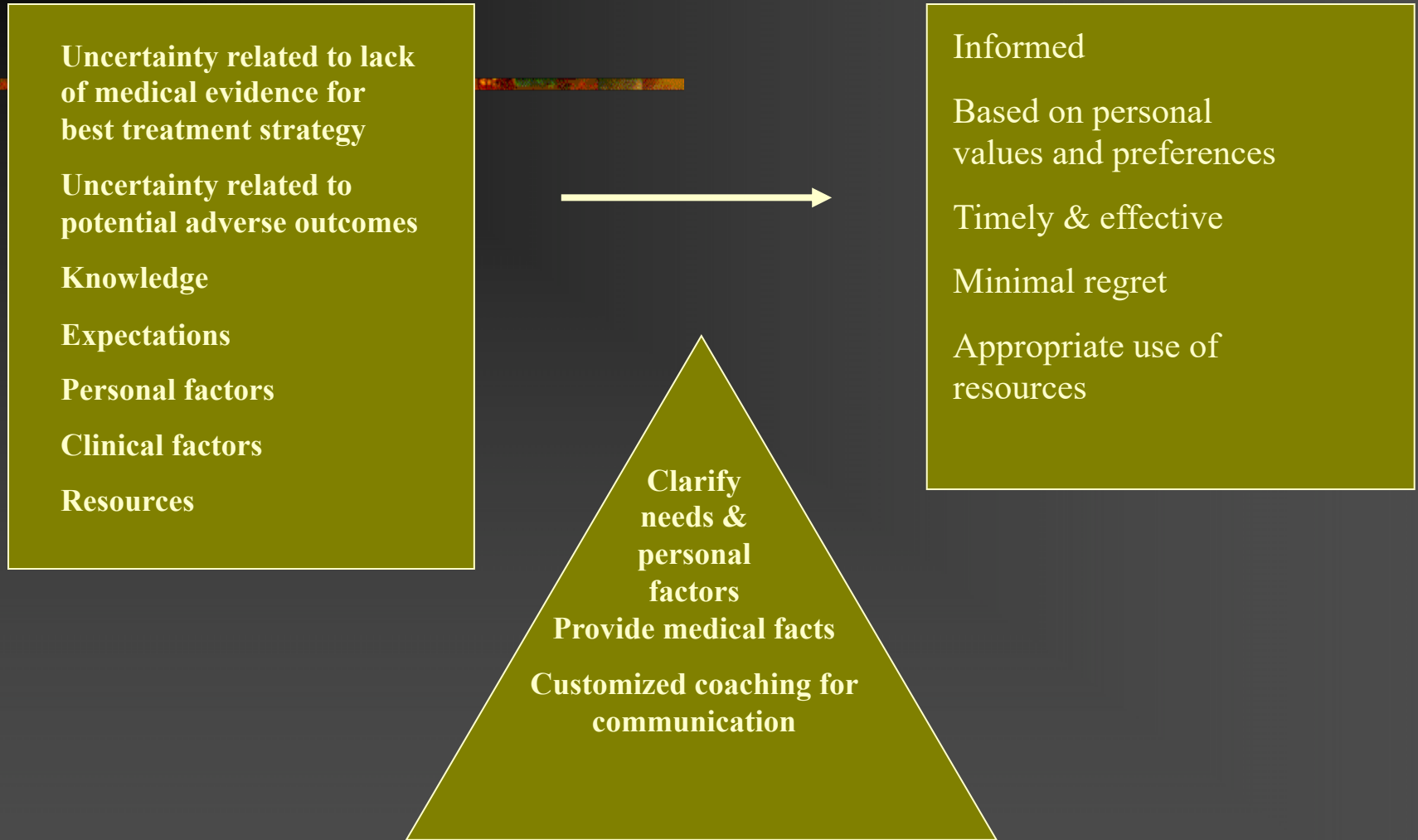
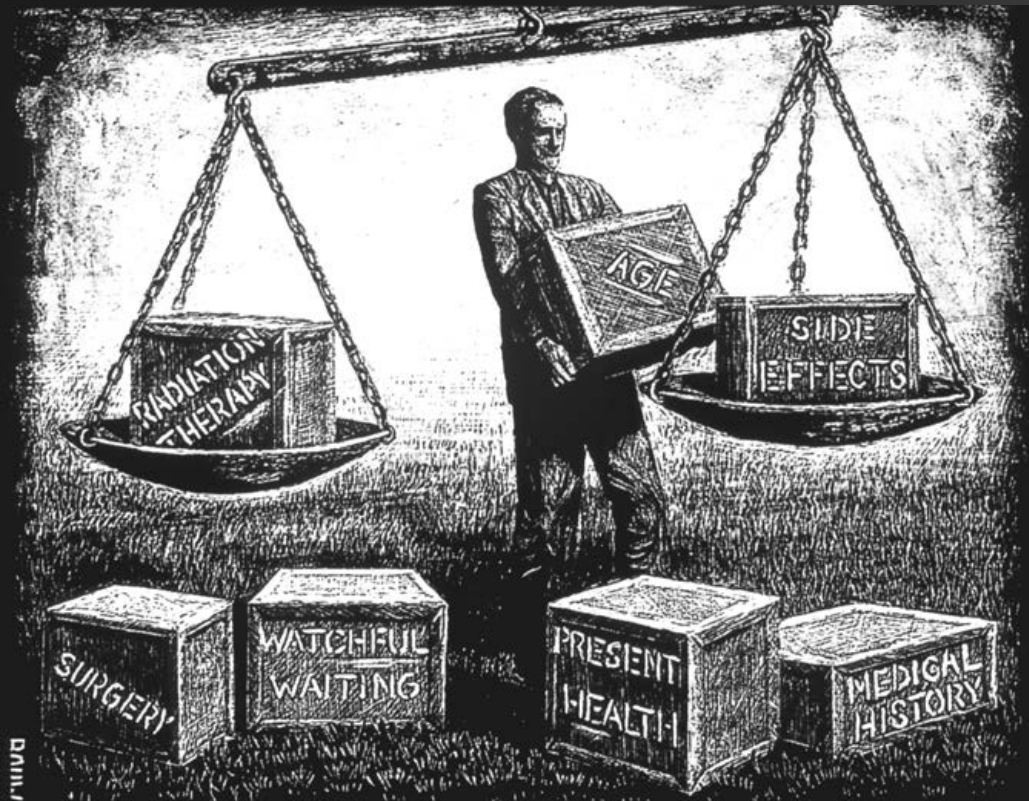


Figure 1. Adapted Ottawa Decision Support Framework

- 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

Landing page

Manage My Trips: Delta Air Lines | P3P (Personal Patient Profile) | X

Personal Patient Profile
PROSTATE

Demos About Help Login [Español](#)

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

By building a personalized profile that provides information about managing diagnosis of prostate cancer.



Clinicians

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

Type here to search

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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

Personal Patient Profile - P3P (NON-PRODUCTION) <https://p3p.cirg.washington.edu/demo/p3p/statistics>

P3P Personal Patient Profile
PROSTATE

Help Log Out

My Home My Top Concerns Statistics My Decision Role More About Prostate Cancer What Do You Think?

Statistics

Click to see other topics:

- ✓ Surviving prostate cancer
- ✓ Bladder problems
- ✓ Sexual problems
- ✓ Bowel problems

It may help you think about your care decision to understand prostate cancer statistics, the numbers that tell what happens to men with prostate cancer. You will probably read or hear many of these numbers. Statistics based on large numbers of men with prostate cancer can say how likely you are to experience things in the future. But no one can know for sure exactly what will happen for you.

You can always ask your doctor to explain how the statistics you see may apply to you or men like you. Below are some real statistics about prostate cancer that also explain in general how to read statistics. If you see links on the left, you can use them to see statistics about other prostate cancer topics, too.

Bladder problems

You may see statistics about prostate cancer treatments causing **bladder** or urinary problems (**incontinence**). Percent incontinence is a statistic that tells you the number of men out of 100 who will not be able to control their **urine** after having a treatment. This can mean:

- No control of urine at all, constant leaking
- Some control, with some leaking
- Waking up to **urinate** 4 to 6 times each night
- Feeling like you have to urinate right away


Research shows that about 13% of men who have surgery or **radiation** for prostate cancer will have long-term bladder problems. This statistic means that about 13 out of every 100 men who have surgery or radiation will have one of these problems for the rest of their lives. It does NOT mean that men will have bladder problems 13% of the time.

Here is a picture (or graph) to help explain. The graph applies to men of all races (black, white, Hispanic, Asian, etc.).

BLADDER INCONTINENCE AFTER TREATMENT FOR PROSTATE CANCER

After treatment about 13% of men will lose some ability to control their urine for the rest of their lives. 13% is 13 men out of 100.

The other about 87% of men will get urine control back at some point after treatment. 87% is 87 men out of 100.



Next Top >: **Sexual problems** > or Skip to Next Section: **My Decision Role** >>

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
-

P3P RCT I (2007-2011)



Urologic Oncology: Seminars and Original Investigations 31 (2013) 1012–1021

UROLOGIC
ONCOLOGY

Original article

The Personal Patient Profile-Prostate decision support for men with localized prostate cancer: A multi-center randomized trial[☆]

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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 Home](#)[My Top Concerns](#)[Statistics](#)[My Decision Role](#)[More About Prostate Cancer](#)[What Do You Think?](#)

Click to see other topics:

Outcomes[✓ Years I Expect to Live](#)[✓ Bladder Function](#)[✓ Sexual Function](#)[✓ Bowel Function](#)**Lifestyle**[✓ Work or Occupation Activities](#)[✓ Recreational Activities](#)**People**[✓ Spouse/Partner](#)[✓ Co-worker](#)[✓ Friend](#)[✓ Family Member](#)**Current Symptoms**[✓ Bladder](#)[✓ Sexual](#)[✓ Bowel](#)

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



Donna Berry

DOB: 1978-06-25 (40 yo)

Patient Report Date: 2016-06-22

Option Preference

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.

Influential Personal Factors



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

Higher scores indicate better QOL



EPIC Domains

Urinary Incontinence

Frequency	More than once a week
Dribbling	Frequent dribbling
Pad use	2 pads per day
Leaking	Big Problem

Urinary Irritation/Obstruction

Pain/burning	No problem
Bleeding	No problem
Stream	Small Problem
Frequency	Big Problem

Bowel

Urgency	No problem
Frequency	No problem
Control	No problem
Blood	No problem
Abd/pelvic/rectal pain	No problem
Overall bowel	No problem

Sexual

Erectile ability	Very Poor to None
Orgasm ability	Very Poor to None
Erections quality	None at all
Erections when I want	Never
Overall sexual ability	Very good
Overall sexual problem	Very small problem

Vitality/Hormonal

Hot flashes	No problem
Breasts tender/larger	Big Problem
Feeling depressed	No problem
Energy	No problem
Weight change	Big Problem

Sexual Interest, Activity and Satisfaction (Past 4 weeks)

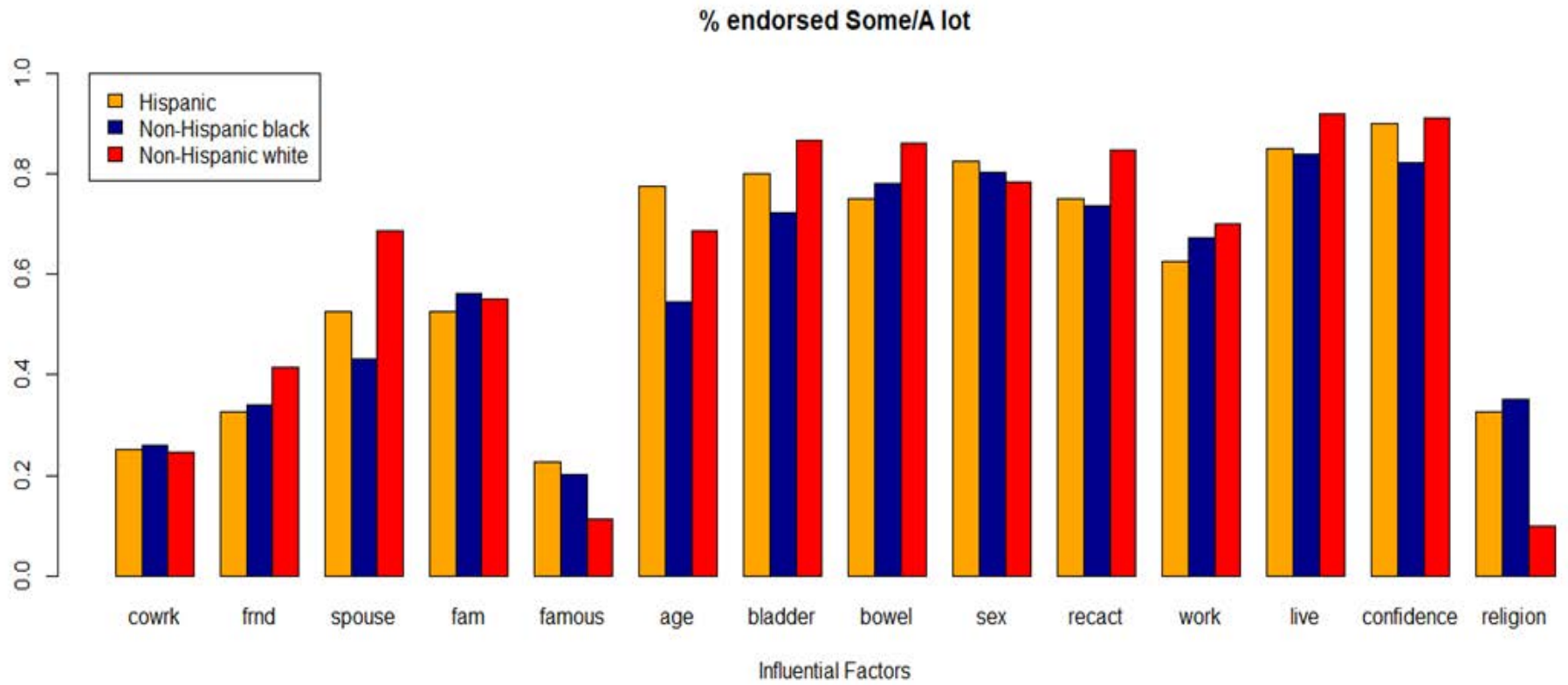
Interest level	Quite a bit	Use of erectile aids	4 or more times
Activity level	4 or more times	Erectile aids:	
Satisfaction	Somewhat	Pills, Penile Injection, Vacuum Erection Device, Other: Fancy machine	

RCT-2013 to 2016

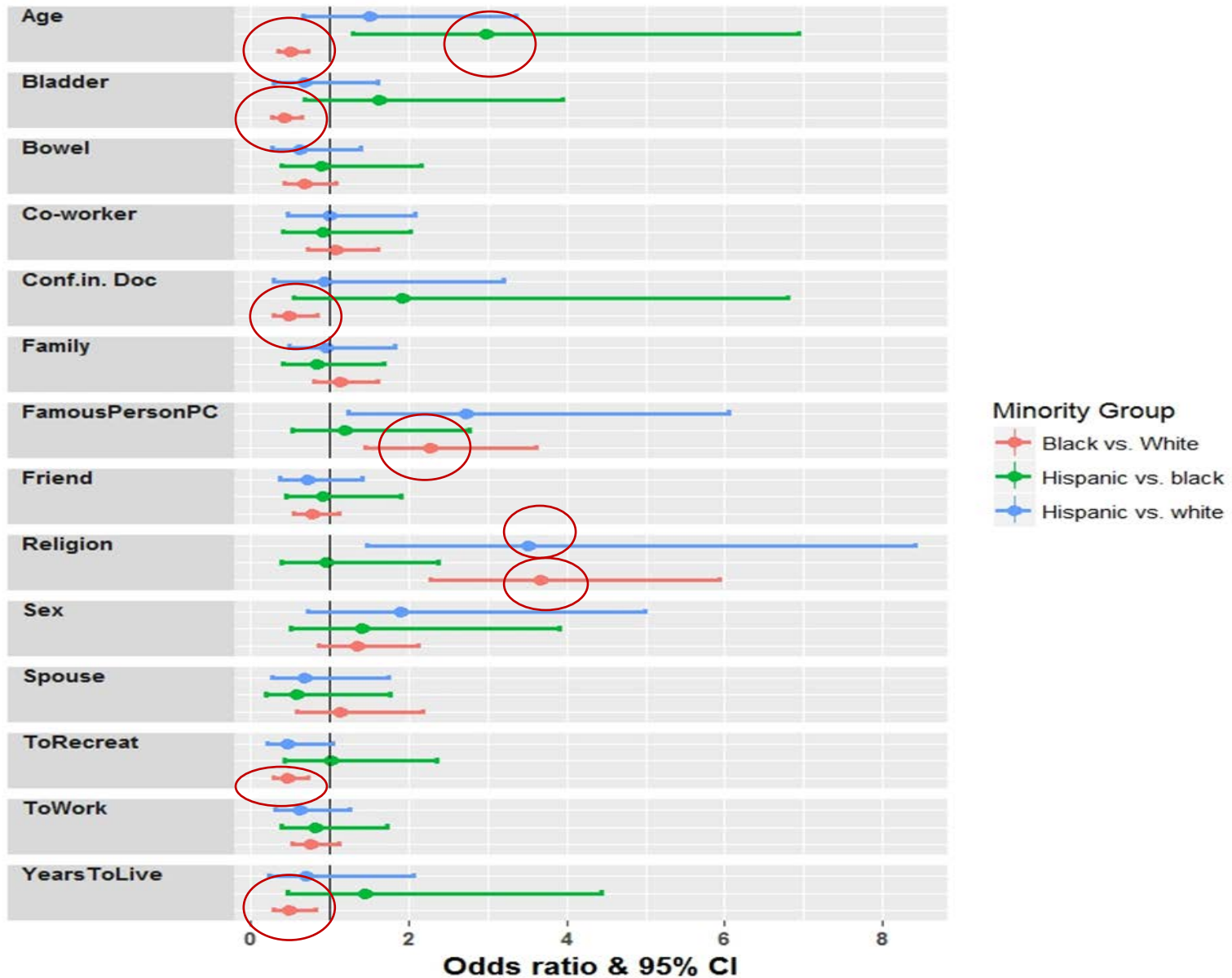
- Sites in Boston, MA, Atlanta, GA, Charlottesville, VA & southern California.
- 392 men were randomized (198 intervention; 194 usual care) and 305 men returned 1-month outcomes (152;153).
 - Diverse sample with regard to race, income and education
- The adjusted, multivariable model revealed significantly 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



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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