The Treatment Seeking Experiences of Men Diagnosed with Prostate Cancer in Pennsylvania

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My motivation: Understand the multi-dimensional role of access to care in racial disparities in prostate cancer treatment
Prostate Cancer in the US

- Most common type of cancer among men of all races
- Incidence is 128.36 per 100,000 men
  - In 2011, over 209,000 men were diagnosed
- Second leading cause of cancer death among men
  - In 2011, almost 28,000 men died from prostate cancer

Prostate Cancer Diagnosis & Treatment

Prostate Screening Tests
- Prostate-specific antigen (PSA) test
- Digital rectal exam (DRE)

Diagnosis
- Prostate biopsy
- Ultrasound

Treatment
- Surgery to remove prostate
- Radiation therapy
- Hormone therapy
- Active surveillance
# Screening for Prostate Cancer

## Clinical Summary of U.S. Preventive Services Task Force Recommendation

<table>
<thead>
<tr>
<th>Population</th>
<th>Adult Males</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendation</strong></td>
<td>Do not use prostate-specific antigen (PSA)-based screening for prostate cancer.</td>
</tr>
<tr>
<td><strong>Grade</strong></td>
<td>D</td>
</tr>
</tbody>
</table>

### Screening Tests

Contemporary recommendations for prostate cancer screening all incorporate the measurement of serum PSA levels; other methods of detection, such as digital rectal examination or ultrasonography, may be included. There is convincing evidence that PSA-based screening programs result in the detection of many cases of asymptomatic prostate cancer, and that a substantial percentage of men who have asymptomatic cancer detected by PSA screening have a tumor that either will not progress or will progress so slowly that it would have remained asymptomatic for the man's lifetime (i.e., PSA-based screening results in considerable overdiagnosis).

### Interventions

Management strategies for localized prostate cancer include watchful waiting, active surveillance, surgery, and radiation therapy. There is no consensus regarding optimal treatment.

### Balance of Harms and Benefits

The reduction in prostate cancer mortality 10 to 14 years after PSA-based screening is, at most, very small, even for men in the optimal age range of 55 to 69 years. The harms of screening include pain, fever, bleeding, infection, and transient urinary difficulties associated with prostate biopsy, psychological harm of false-positive test results, and overdiagnosis. Harms of treatment include erectile dysfunction, urinary incontinence, bowel dysfunction, and a small risk for premature death. Because of the current inability to reliably distinguish tumors that will remain indolent from those destined to be lethal, many men are being subjected to the harms of treatment for prostate cancer that will never become symptomatic. The benefits of PSA-based screening for prostate cancer do not outweigh the harms.

### Other Relevant USPSTF Recommendations

Recommendations on screening for other types of cancer can be found at [www.uspreventiveservicestaskforce.org](http://www.uspreventiveservicestaskforce.org).

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Incidence Rates by Race/Ethnicity

Combined data from the National Program of Cancer Registries as submitted to CDC and from the Surveillance, Epidemiology and End Results program as submitted to the National Cancer Institute in November 2013.
Death Rates by Race/Ethnicity

Mortality source: U.S. Mortality Files, National Center for Health Statistics, CDC.
Key Studies


- African Americans have a 33% higher risk of dying of cancer than whites
- Racial disparities in mortality are not completely explained by incidence and stage of cancer at diagnosis
- Inequities in the receipt of prostate cancer treatment

Chornokur et al. (2011)

- African Americans with later stages of prostate cancer were less likely to undergo radical prostatectomy than whites, but more likely to receive conservative management
- These treatment differences may reflect African Americans' greater likelihood for presenting with pathologically advanced PCa for which surgery has limited effectiveness


Study Aims

**SA1:** Determine the relationship between spatial measures of access to prostate cancer care and racial differences in prostate cancer treatment

**SA2:** Determine the relationship between patient experiences of access to cancer care and racial differences in prostate cancer treatment

**SA3:** Explore differences in access to prostate cancer providers with different characteristics between black and white men
Study Aims

Investigate the contribution of a multi-dimensional picture of access to prostate cancer care to racial differences in treatment of localized prostate cancer in 8 counties in the Greater Philadelphia area.
Access
Access

Availability

Accessibility

Accomodation
Five Dimensions of Access

- Availability
- Acceptability
- Affordability
- Accessibility
- Accommodation

Methods

Enroll a cohort of black and white men diagnosed with prostate cancer between 2012 and 2015.

Ask patients to complete mailed survey that measures the multiple dimensions of health care access as they pertain to prostate cancer treatment.

Interviews were conducted with a subset of the sample of subjects who completed the mailed survey to understand how they chose providers and treatment.
### Demographic Characteristics (Overall)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N (%) or Mean</th>
<th>Characteristics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td>65.12 (8.36)</td>
<td><strong>Employment Status</strong></td>
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<td><strong>Educational Attainment</strong></td>
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<td>Employed</td>
<td>488 (41.1%)</td>
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<td>8th grade or less</td>
<td>34 (2.9%)</td>
<td>Unemployed</td>
<td>28 (2.3%)</td>
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<td>Some high school</td>
<td>69 (5.8%)</td>
<td>Disabled</td>
<td>88 (7.4%)</td>
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<td>High school graduate</td>
<td>302 (25.4%)</td>
<td>Retired</td>
<td>532 (44.8%)</td>
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<tr>
<td>Some college</td>
<td>258 (21.7%)</td>
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<tr>
<td>College graduate</td>
<td>191 (16.1%)</td>
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<tr>
<td>More than college</td>
<td>311 (26.2%)</td>
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<tr>
<td><strong>Total Household Income</strong></td>
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<tr>
<td>&lt;$15,000</td>
<td>90 (7.6%)</td>
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<td>$15,000 - $25,000</td>
<td>68 (5.7%)</td>
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<td>75 (6.3%)</td>
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<td>112 (9.4%)</td>
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<td>$50,000 - $75,000</td>
<td>187 (15.8%)</td>
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<td>$75,000 - $100,000</td>
<td>169 (14.2%)</td>
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<tr>
<td>&gt;$100,000</td>
<td>367 (30.9%)</td>
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<tr>
<td><strong>Race</strong></td>
<td></td>
<td>White</td>
<td>1817 (82.8%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Black</td>
<td>379 (17.2%)</td>
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</table>
Qualitative Interviews

53 semi-structured interviews with men who were diagnosed with prostate cancer

Interviews conducted over the phone - Avg 23 min long

Men offered compensation for participation
### Demographic Characteristics (Qual. Int.)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N (%) or Mean</th>
<th>Characteristics</th>
<th>N (%)</th>
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<td>Employment Status</td>
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<td>20 (38.5%)</td>
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<td>8th grade or less</td>
<td>1 (1.9%)</td>
<td>Unemployed</td>
<td>2 (3.8%)</td>
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<tr>
<td>Some high school</td>
<td>7 (13.2%)</td>
<td>Disabled</td>
<td>50 (38.4%)</td>
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<td>High school graduate</td>
<td>11 (20.8%)</td>
<td>Retired</td>
<td>5 (9.6%)</td>
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<tr>
<td>Some college</td>
<td>11 (20.8%)</td>
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<tr>
<td>College graduate</td>
<td>9 (17%)</td>
<td>White</td>
<td>40 (75.5%)</td>
</tr>
<tr>
<td>More than college</td>
<td>13 (24.5%)</td>
<td>Black</td>
<td>13 (24.5%)</td>
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<tr>
<td>Total Household Income</td>
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<td>&lt;$15,000</td>
<td>6 (12%)</td>
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<td>5 (4%)</td>
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<td>3 (6%)</td>
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<td>$50,000 - $75,000</td>
<td>13 (26%)</td>
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<td>$75,000 - $100,000</td>
<td>4 (8%)</td>
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<tr>
<td>&gt;$100,000</td>
<td>16 (32%)</td>
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Analysis

Interview tapes transcribed by transcription company

De-identified transcripts uploaded into NVivo 10™
Code book created
Systematic thematic analysis
Preliminary Findings: The treatment seeking experiences of black men diagnosed with prostate cancer
Common Themes

Availability - Relied on and trusted doctor’s referrals

Accessibility - Convenient travel distance to provider’s office

Accommodation - Office hours were convenient

Affordability - Mixed experiences with insurance

Acceptability - Looks for provider who takes the time to listen

Fear of cancer

Treatment decisional regret
Expressed in their words
“[Urologist’s name], I trusted him because [my doctor] referred me to him ... so I just relied on his information. So I went to him and he told me, he said it was aggressive, that I had to get it right away.” - Participant A

“Well, I just wanted to get it done with... I’m not ready to die now. I don’t think I’m ready to die. And I know cancer is a serious situation... I’m just saying that cancer is very serious, and when someone tell you, you got cancer real bad, then you got cancer real bad. And you take that opinion and try to get help. And that’s what I did.” - Participant B
Mixed experiences with insurance

“I got Medicare and my – up until now, I didn’t have to have to pay one dime.” - Participant E

“The insurance plus the – who was referring me, but the insurance was number one. I had to go to the doctor who accepted my insurance, because I had called Mercy and a lot of doctors around here in closer areas don't accept it, so I had to go to the people accepting my insurance...And the rest of them that took my insurance, they lived nowhere around, I mean nowhere close at all.” - Participant F
Treatment decisional regret

“But in reality I wished I didn't get the operation. I wish I would have just kept on because from what I hear it comes back in a couple of years somewhere else anyway. But it still messed up my sex life. Because I wasn't ever notified – I wasn't ever told that I wouldn't have erections anymore...I wouldn't – that way I could still try to get a couple of kids before I went completely down and done. I could still try to have me another baby. And that's what hurt.” - Participant F
Implications

Develop strategies to improve knowledge about whether to undergo active treatment and treatment side effects

Develop strategies to ensure that patients have more “active” roles in the process for their prostate cancer care
Next Steps

Continue thematic analysis for all qualitative interviews

Compare narratives of treatment seeking experiences for men who were in a high supply group to men who were in a low supply group

Compare the narratives of treatment seeking experiences for men who played a more “active” role in decision-making for their prostate cancer care

Manuscripts to be developed for publication

September 2015
Strengths and Limitations

Strengths
   Interview guide

Limitations
   Selection bias
   Retrospective study design
   Poor external validity
Reflections

Develop qualitative data collection, analysis, and interpretation skills

Understand components of access to care and how it applies to treatment seeking experiences for men with prostate cancer

Understand mechanics of study implementation
Acknowledgements

David Grande, MD, MPA
Linda Crossette, MPH
Christian Stillson, MPH
Hannah Lev, MSW candidate
Sarah Li, MPH candidate
Joanne Levy, MBA
Safa Browne, MPH
2015 SUMR Cohort


Questions