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Reading Between the Lines: Health Literacy in Prostate Cancer Care

Developing Evidence-Based Interventions to Support Patients with Low Health Literacy

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5.21.2026

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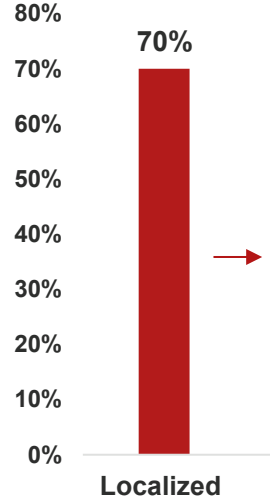
Epidemiological Snapshot

Estimated new cancer cases in 2024 in males (excluding skin cancer)

Prostate	299,010	29%
Lung & bronchus	116,310	11%
Colon & rectum	81,540	8%
Urinary bladder	63,070	6%
Melanoma of the skin	59,170	6%
Kidney & renal pelvis	52,380	5%
Non-Hodgkin lymphoma	44,590	4%
Oral cavity & pharynx	41,510	4%
Leukemia	36,450	4%
Pancreas	34,530	3%
All sites	1,029,080	



Stage distribution (%) of prostate cancer between 2016-2020



209,000 newly diagnosed patients with localized PC

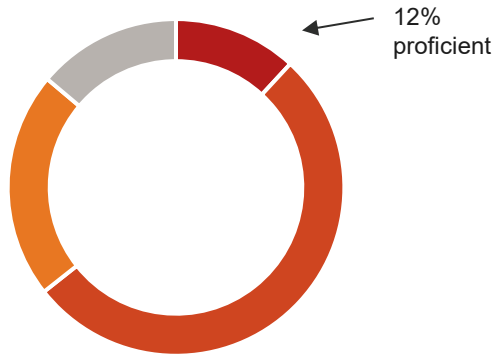
- Low-risk, 24%
- Favorable-intermediate risk, 16%
- Unfavorable intermediate-risk, 30%
- High-risk, 31%

Health literacy is a significant driver of patient outcomes

Health Literacy

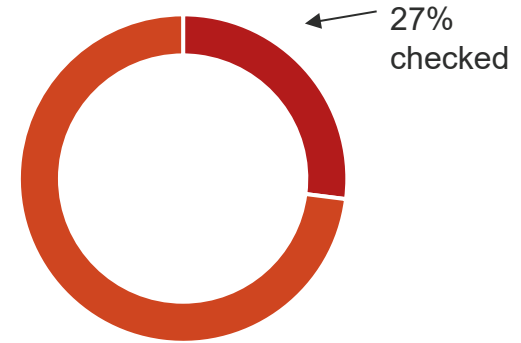
Health literacy, or the degree to which individuals have the ability to find, understand, and use information to inform health-related decisions, is an important determinant of health

Health literacy in US



■ Proficient ■ Intermediate ■ Basic ■ Below basic

Healthcare provider checked understanding



■ Checked ■ Not checked



The impact of health literacy on outcomes, including mortality, has been studied across medical conditions such as diabetes, heart failure, and renal transplant

Health Literacy and Prostate Cancer

- Studies on the role of HL in prostate cancer are largely limited to screening and its role in advanced disease is poorly understood
- The diagnosis of prostate cancer involves navigating complex treatment regimens, ongoing disease management, and healthcare system barriers

→ Challenging for those with low health literacy

1. Localized Prostate cancer
2. Advanced Prostate cancer

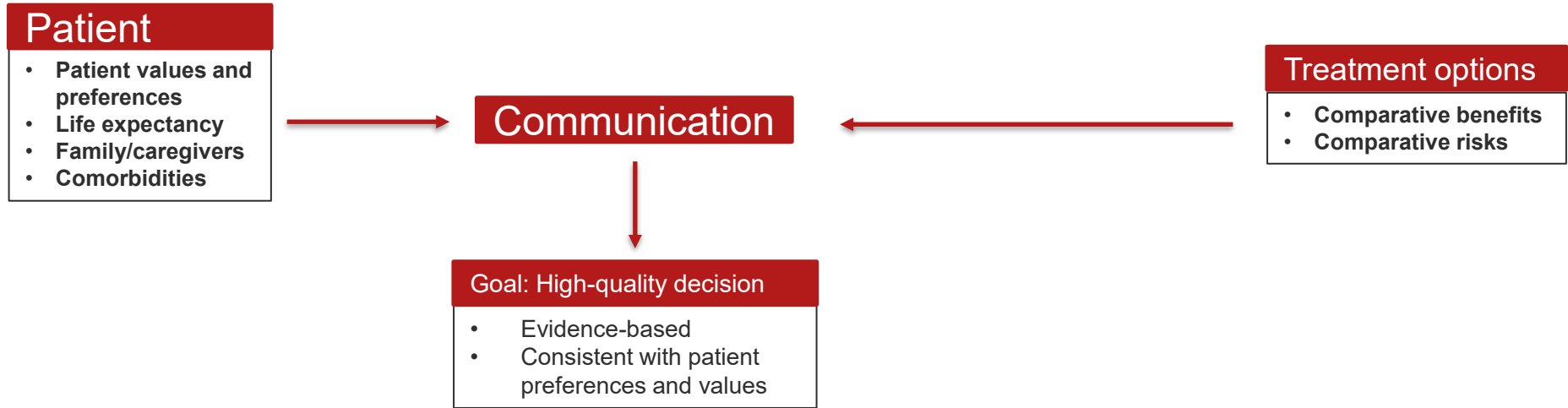
How do Patients with Localized Disease Choose Treatments Nowadays?

Surgery, radiation, or surveillance...

Shared Decision-Making

- Clinicians and patients collaborate and share the best available evidence when making decisions
 - If there are several reasonable alternatives, they are explicitly compared using evidence about relevant harms and benefits
 - Decisions are informed by knowledge about the patient's condition, evidence applicable to it, and the patient's goals and preferences
- Started in the early 1980s, and academic interest surged in the late 1990s, fueled by the parallel innovation of patient decision aids
- Shared decision-making and patient decision aids mentioned in the Affordable Care Act in 2010, initialing a policy emphasis

Shared Decision-Making in Localized Prostate Cancer

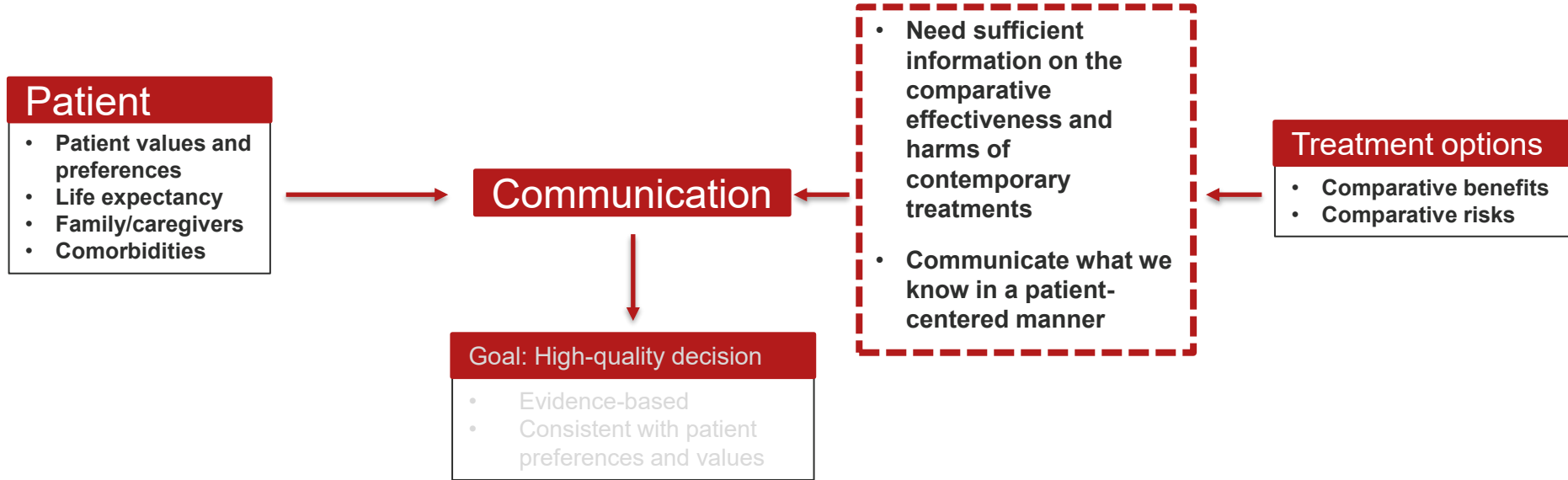


AUA Guideline Articles

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Clinically Localized Prostate Cancer: AUA/ASTRO Guideline, Part I: Introduction, Risk Assessment, Staging, and Risk-Based Management

Shared Decision-Making in Localized Prostate Cancer

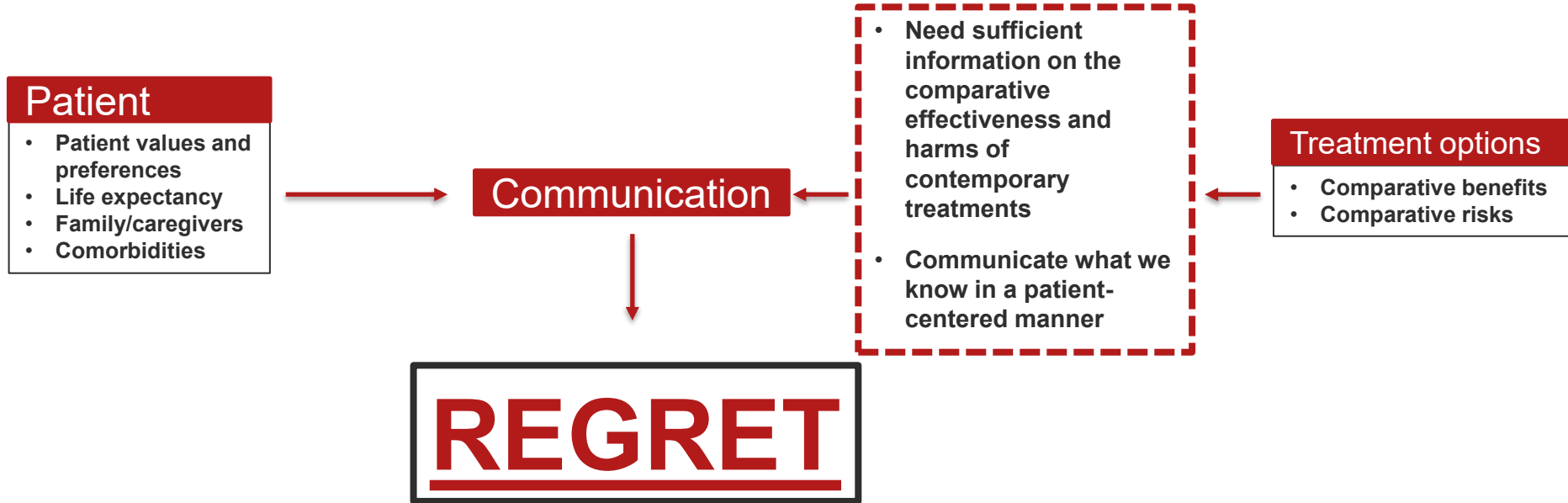


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Regret = Managing Expectations

JAMA Oncology | Original Investigation

Association of Treatment Modality, Functional Outcomes, and Baseline Characteristics With Treatment-Related Regret Among Men With Localized Prostate Cancer

Christopher J. D. Wallis, MD, PhD; Zhiguo Zhao, MS; Li-Ching Huang, PhD; David F. Penson, MD, MPH; Tatsuki Koyama, PhD; Sherrie H. Kaplan, PhD, MS, MPH; Sheldon Greenfield, MD; Amy N. Luckenbaugh, MD; Zachary Klaassen, MD, MSc; Ralph Conwill, BS; Michael Goodman, MD, MPH; Ann S. Hamilton, PhD, MA; Xiao-Cheng Wu, MD, MPH; Lisa E. Paddock, PhD, MPH; Antoinette Stroup, PhD; Matthew R. Cooperberg, MD, MPH; Mia Hashibe, PhD; Brock B. O'Neil, MD; Karen E. Hoffman, MD, MHSc, MPH; Daniel A. Barocas, MD, MPH

- Regret reported by more than 1 in 10 patients with localized prostate cancer
 - 16% radical prostatectomy
 - 11% radiation therapy
 - 7% active surveillance
- Mediated by functional outcomes (sexual function) and patient expectations (perception of adverse effects compared with expectations)
- Greater participation in decision-making → Less likely to experience regret

Comparative Benefits vs Harms

- Benefits → Cancer Outcomes (our interpretation)
 - Low and favorable-intermediate risk: No differences in survival between immediate treatment vs surveillance
 - Unfavorable intermediate- and high-risk: Immediate treatment lowers risk of adverse oncologic outcomes (surgery/radiation are similar, but one may be preferred over the other)
- Harms → Side effects (Quality of Life)
 - Easy to name but difficult to quantify

Easy to Name the Adverse Outcomes...

- **Surgery**
 - Surgical complications/risks
 - Urinary incontinence and erectile dysfunction
- **Radiation**
 - Irritative bowel and urinary symptoms
 - Rare: strictures, fistulae, hemorrhagic cystitis/prostatitis, secondary cancers
- **Surveillance**
 - Anxiety
 - Burden from repeat testing/biopsy
 - Risk of disease progression


Comparative Benefits vs Harms

- Benefits → Oncologic Outcomes (our interpretation)
 - Low and favorable-intermediate risk: No differences in survival between immediate treatment vs surveillance
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- Harms → Adverse effects (Quality of Life)
 - Easy to name but difficult to quantify
 - **Most important outcome for most patients because survival rates are high and oncologic outcomes are similar**



Comparative Effectiveness Analysis of Surgery And Radiation for Prostate Cancer

- Robotic prostatectomy, intensity-modulated radiotherapy, and active surveillance
- 10-year prospective population-based study of 2,445 patients
 - Sexual function
 - Urinary function: Incontinence and irritative/obstructive
 - Bowel function
 - Hormone therapy side effects
- Stratification by risk category (prognosis), different risk groups have different guideline-recommended options, with distinct side-effect profiles



Research

JAMA | **Original Investigation**

Functional Outcomes After Localized Prostate Cancer Treatment

Bashir Al Hussein Al Awamlh, MD; Christopher J. D. Wallis, MD, PhD; David F. Penson, MD, MPH; Li-Ching Huang, PhD; Zhiguo Zhao, MS; Ralph Conwill, BS; Ruchika Talwar, MD; Alicia K. Morgans, MD, MPH; Michael Goodman, MD, MPH; Ann S. Hamilton, PhD, MA; Xiao-Cheng Wu, MD, MPH; Lisa E. Paddock, PhD, MPH; Antoinette Stroup, PhD; Brock B. O'Neil, MD; Tatsuki Koyama, PhD; Karen E. Hoffman, MD, MHSc, MPH; Daniel A. Barocas, MD, MPH



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Main Findings

- **Less aggressive cancers (surgery vs radiation vs surveillance)**
 - Surgery: more urinary leakage long-term
 - Sexual function: similar across all treatments by 10 years
 - Bowel function: similar across all treatments
- **More aggressive cancers (surgery vs radiation + hormones)**
 - Surgery: more urinary leakage
 - Radiation + hormones: more bowel problems and hormone side effects (low energy)
 - Sexual function: similar between the two
- **Bottom line**
 - No treatment is "best" for everyone
 - Each comes with different trade-offs
 - Choice should match what matters most to the patient

Specific Key “Quality of Life” Findings

- No differences in sexual function impairment between surgery and radiation with hormonal treatment (androgen deprivation therapy) for patients with unfavorable prognosis cancer → importance of counseling patients based on cancer prognosis → adverse effects of treatments on sexual function may be deemphasized in decision making for some men
- Radiation therapy combined with hormone therapy (androgen deprivation therapy) was associated with slightly worse bowel and hormonal side effects at 10 years for patients with unfavorable prognosis prostate cancer
- Results highlight the benefits of active surveillance, when safe from a cancer control perspective for patients with favorable-prognosis prostate cancer, by avoiding adverse effects associated with other treatment options

Next steps for localized PC

- Communication is key!
- Personalized functional outcomes prediction tool tailored for patients with low health literacy
- Community-engaged research to illicit feedback through focus groups to refine the tool into a progressive web app

Click [HERE](#) to see estimated chances for specific issues after treatment.

Click [HERE](#) to see how much your estimated functions will change after treatment.

I want to see:

my chances at specific times

After this treatment:

Surgery with radical prostatectomy

After this much time from now:

3 years

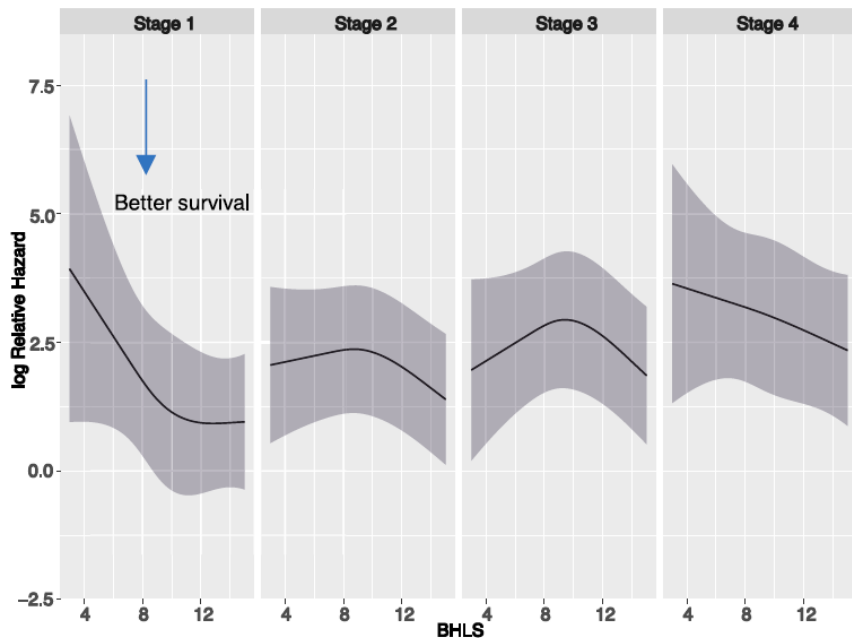
For this type of problem:

Erections NOT firm enough for sex

3 years after Surgery with radical prostatectomy : there is a 82% chance of you having erections NOT firm enough for sex .

- 1. Localized Prostate cancer**
- 2. Advanced Prostate cancer**

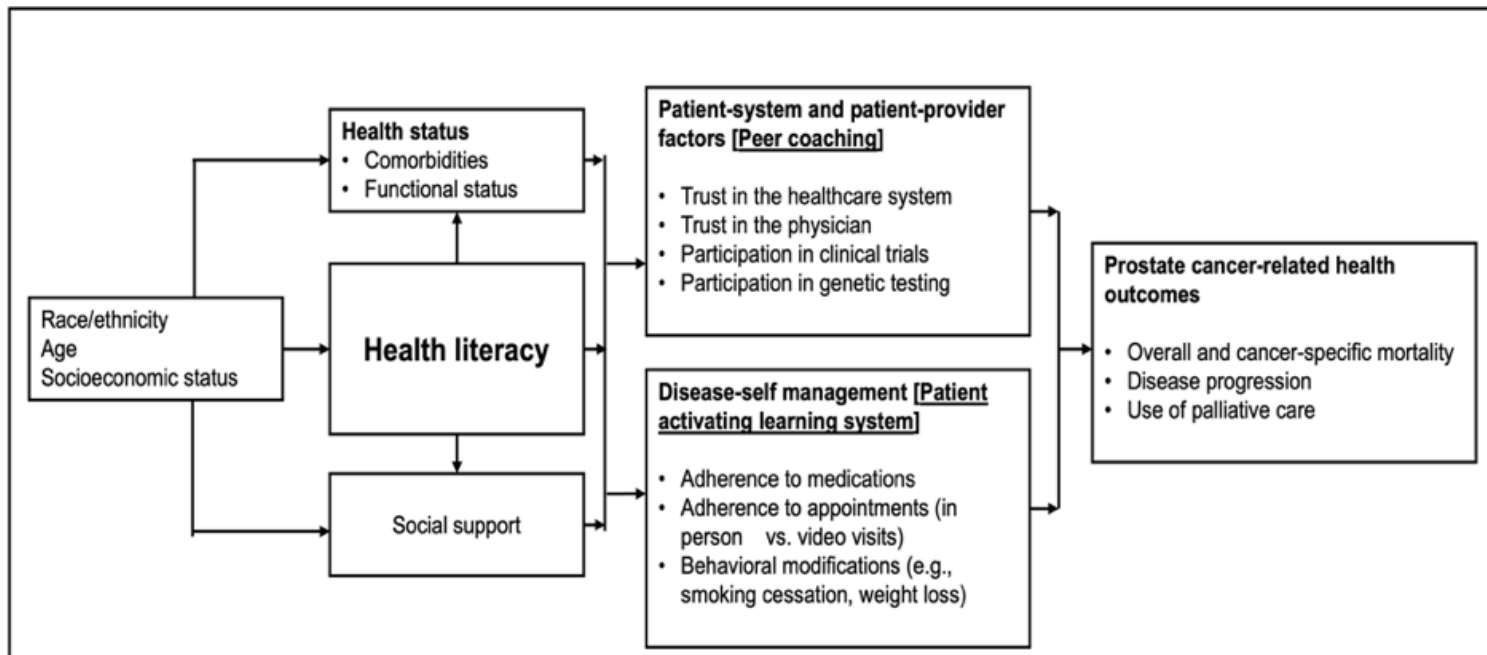
Health Literacy and Prostate Cancer



Partial effect plots of adjusted log relative hazard of mortality over Brief Health Literacy Screen scores within each stage for patients with PC (n=1629) treated at tertiary cancer center between 2008-15

- Low vs adequate health literacy = 1.6-year shorter survival
- Relationship was evident in patients with advanced disease
- **Low vs adequate health literacy = two- to threefold higher mortality rate**

Conceptual Framework – Role of Health Literacy in Advanced Prostate Cancer



New York City

- Recent data from New York suggest that 1 in 5 patients experience inadequate HL support from healthcare organizations
- WCM study of cancer patients in NYC found that health literacy is a driver of disparities in neighborhoods with disproportionately high prostate cancer mortality

→ NYC's diverse population provides an ideal setting to investigate the association between HL and PC outcomes and to develop and implement targeted interventions

Overarching Goal



Leveling the playing field in prostate cancer = Reliable and easy-to-understand information

Research Objectives for localized disease

- Assess the role of health literacy in the care of patients with localized prostate cancer among a diverse group of patients in New York City
- Develop an intervention in the form of a functional outcomes prediction tool for prostate cancer treatments (e.g., sexual and urinary functions) that is easily understandable and accessible for men with prostate cancer, irrespective of health literacy level, to help in treatment decisions.

Aims of Grant Proposal

- **Collect information on health literacy and treatment for patients with prostate cancer using surveys to understand how health literacy affects treatment decisions (regret and conflict)**
- **Adapt a tool that helps patients understand what to expect after prostate cancer treatment, making it suitable for men with different levels of health literacy**
 - **Mobile WebApp**
- **Test the tool and assess how well it works in real life in patients with prostate cancer**

I want to see:

My chance at specific time

After this treatment:

Surgery with radical prostatectomy

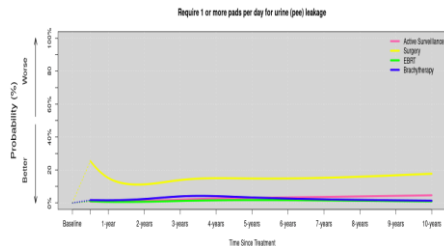
After this much time from now:

5 years

For this type of problem:

Erections NOT firm enough for sex

5 years after Surgery with radical prostatectomy : there is a 40% chance of you having erections NOT firm enough for sex.



Community-Engaged Research

- Prostate cancer patients
- Health educators
- Patient advocates
- Community physicians



Research Objectives for Advanced disease

- Study the factors through which HL affects PC outcomes
- Apply these findings to develop and implement HL-tailored interventions, specifically PALS and peer coaching
- Leverage our expertise and established relationships with community stakeholders to optimize these interventions for patients with low HL
- **Central hypothesis: Low HL contributes to worse PC-related outcomes through patient-system, patient-provider, and disease self-management factors that can be targeted with evidence-based interventions**

Aims of Grant Proposal

- **Compare patient-system, patient-provider, and disease-self management factors that contribute to prostate cancer-related outcomes between men with low and adequate health literacy**
- **Assess patient-system, patient-provider, and disease-self management factors contributing to prostate cancer-related outcomes using a community-engaged approach**
- **Evaluate the feasibility and implementation outcomes of peer coaching and Patient Activated Learning System–based approaches tailored for men with low health literacy and advanced prostate cancer**

Thank you



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Questions?



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