ASSOCIATION OF COMMUNITY CANCER CENTERS

Comprehensive Care of Patients with Advanced Prostate Cancer through Shared Decision-Making

LANDSCAPE ANALYSIS

ACCC

Association of Community Cancer Centers

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BACKGROUND

The American Cancer Society projects that, in 2021, the number of patients diagnosed with prostate cancer will increase by 30 percent from the year before, and deaths from prostate cancer will increase 2.4 percent.[1] These historic highs mean that nearly 250,000 people will be diagnosed with prostate cancer this year, and more than 34,100 people will die from the disease. Much of these high numbers are related to COVID-19, which caused many people to forego annual checkups and regular prostate exams during the height of the pandemic. Experts expect 2022 numbers to be even higher.[2]

Given the expanding need for prostate cancer care, providers need more resources to help them best serve their growing patient populations. When providers work with their patients to identify the best treatment options available, patients are more confident in their treatment decisions, enabling providers to offer better-quality care.

"Shared decision-making" refers to the process by which patients, their chosen caregiver(s), and providers work together to make fully informed treatment decisions using the best available evidence, incorporating the patient's values and preferences. If this collaborative decision-making fails to happen, the patient is more likely to be dissatisfied and regret the treatment choices they made.[3] This approach is most appropriate when there is more than one reasonable treatment option or when the scientific evidence is not available or is conflicting.[4] When there are multiple reasonable options, the patient's values and preferences become central to the decision-making process. Like other cancers, cancers of the prostate are diagnosed at various stages, which can affect the number of treatment options available.

External factors—such as social determinants of health—can also impact an individual patient's options and access to care, which can in turn influence outcomes. To identify the social determinants of health that may result in the disparities in care that can lead to suboptimal outcomes, this paper pays particular attention to addressing the role that external factors in a patient's life may have on determining treatment.

The process of shared decision-making involves the following steps:

1. **Inviting the patient and any chosen caregiver(s) to participate in decision-making**
2. **Presenting and discussing options, risks, and benefits**
3. **Discussing the patient's values and preferences**
4. **Helping the patient make a decision that is consistent with their goals and preferences**

By reviewing the current state of personal engagement in decision-making for patients with advanced prostate cancer, this paper identifies obstacles to shared decision-making between patients and their providers and proposes new ways to better educate patients about their treatment options.

This information will inform the development of patient and provider surveys that will aim to identify points of confusion and frustration for patients about their treatment options and identify existing practice patterns, barriers to optimal care, and improvement strategies.

For the purpose of this project, patients with advanced prostate cancer include:

- Patients with a biochemical recurrence without metastatic diagnosis after all other treatment options (local radiation, prostatectomy)
- Non-metastatic castration-resistant prostate cancer (nmCRPC)
- Metastatic castration-sensitive prostate cancer (mCSPC)
- Metastatic castration-resistant prostate cancer (mCRPC)

CURRENT TREATMENT LANDSCAPE FOR PROSTATE CANCER

When prostate cancer is diagnosed at an early stage, treatment options such as surgery, radiation, and active surveillance can have similar clinical outcomes. However, individual patients may make very different treatment decisions based on additional factors, such as individual risk profile (based on PSA level and grade group), overall life expectancy, the short-term and long-term side effects of different treatments, and quality of life values and preferences. Similarly, when prostate cancer advances and some treatment options are no longer available, each patient's case is unique, and their engagement in decision-making is important.

For advanced prostate cancer, a number of treatment choices exist:

- **Hormone therapy:** Androgen deprivation therapy has long been a tool for controlling prostate cancer, with medical castration as the preferred method over surgical castration.[4] New generations of androgen receptor inhibitors are moving into clinical practice, offering promise to patients who may have been resistant to previous generations.
- **Chemotherapy:** Cytotoxic chemotherapy can be used alone or in conjunction with hormone therapy.
- **Immuno-oncology therapy:** Currently, personalized vaccine therapy is approved for mCRPC, and anti-PD1 therapy is approved for microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) mCRPC.
- **Clinical trials:** Today's promising clinical research focuses on the role of poly ADP-ribose polymerase (PARP) inhibitors, radiopharmaceuticals, and immuno-oncology therapies.[5]
- **Stopping treatment:** Stopping cancer-directed therapy is always a care option to consider. Patients with advanced prostate cancer may have significant side effects. This is why understanding a patient's values, preferences, and goals is important to providing quality care.

Additionally, radiation may be considered a treatment option in certain cases of advanced prostate cancer, and there is evidence indicating that treating both the primary tumor and oligometastases could improve overall survival.[6] Radiation can also be used for palliative treatment of symptomatic bone metastases, without impacting overall survival. There are benefits and risks to each of these options.

When patients with advanced prostate cancer have more than one possible treatment option, they should be encouraged by their providers to take a range of potential side effects into consideration, including:[3]

- **Physical Impact:** Fatigue, hot flashes, bone pain, osteoporosis, weight loss/gain, foot swelling, pain during urination, frequent night urination, erectile dysfunction, urinary incontinence
- **Psychological Impact:** Depression, anxiety, hopelessness, social isolation
- **System Factors:** Cost of care, family involvement, caregiver burden

Each patient will have different preferences and priorities regarding their care options. In addition to side effects from treatment, patients should also keep in mind that they may also experience side effects from the disease itself, such as urinary urgency, incontinence, nocturia, hematuria, incomplete urinary emptying, or erectile dysfunction.[7]

TIPS TO ACHIEVE SHARED DECISION-MAKING

MANAGE EXPECTATIONS

To participate in their own care decisions, patients should have accurate expectations of specific treatments. Patients with unrealistic expectations are more likely to choose aggressive treatments that negatively impact their quality of life and have a low likelihood of clinical benefit.[8] In one study of 100 patients being treated for metastatic prostate cancer in 2015 and 2016, 33 percent reported that they believed there was some level of likelihood that their metastatic prostate cancer could be cured by systemic treatment—an inaccurate expectation.[9] Seventy-six percent said they believed that they were likely to see some level of symptom relief from treatment, and 95 percent said they believed their treatment would extend their life—both accurate beliefs.

A subgroup analysis revealed that patients who identified as non-White or self-reported excellent or good health were more likely to believe that their treatment had some likelihood of curing their cancer. These subgroups may need more support through the SDM process to accurately understand the benefits and risks of treatment options to make better treatment decisions.

In a previous hypothesis-generating survey in 2014 of 100 patients with metastatic prostate cancer, 68 percent of respondents indicated an unrealistic hope that their cancer was curable.[10] The variables that surveyed patients cited as strongly influencing their treatment decisions included relying on physician treatment recommendations, a desire to feel well enough to spend quality time with loved ones, and the desire to die in a manner consistent with the patient’s wishes. Additional factors that influenced patients’ treatment decisions included the age of the patient, race, marital status, employment status, and self-reported health—a range of factors that should be considered in shared decision-making. By including patients in their treatment decisions, providers can better convey to them accurate expectations about the effectiveness of different types of treatments.

INCLUDE PARTNERS

Caregivers who are the partners of patients with advanced prostate cancer are often asked to share in treatment decision-making with their loved ones. Ensuring that care partners have realistic expectations about treatment side effects is important. In one study that evaluated the impact of prostate cancer on the partners of patients, researchers surveyed 88 patients with prostate cancer and their female partners about their satisfaction with treatment, their sexual relationship, and the patients' sexual function at the time of diagnosis, six months after diagnosis, and 12 months after diagnosis.[11] Despite being generally satisfied with treatment, at six months, the partners reported increasing problems with their sexual relationship over time, likely due to expectations of improved sexual function that were not met.

TAKE TIME FROM DIAGNOSIS INTO ACCOUNT

The amount of time that has passed since a patient's diagnosis can also be an important variable in decision-making. In a 2018 qualitative study of an interactive decision aid with 35 pairs of patients diagnosed with mCRPC and their decision partners, patients who were more than six months out from their diagnosis of metastatic prostate cancer had different needs compared to those who had been diagnosed less than six months ago.[8] For example, patients with a recent diagnosis said the role of their physicians in decision-making was more important than patients who had been diagnosed for some time, likely due to the immediate focus on medical diagnosis and treatment. Patients who had been living with metastatic disease longer were more likely to discuss decisions with their nurses, likely because those patients were considering changing or stopping treatment.

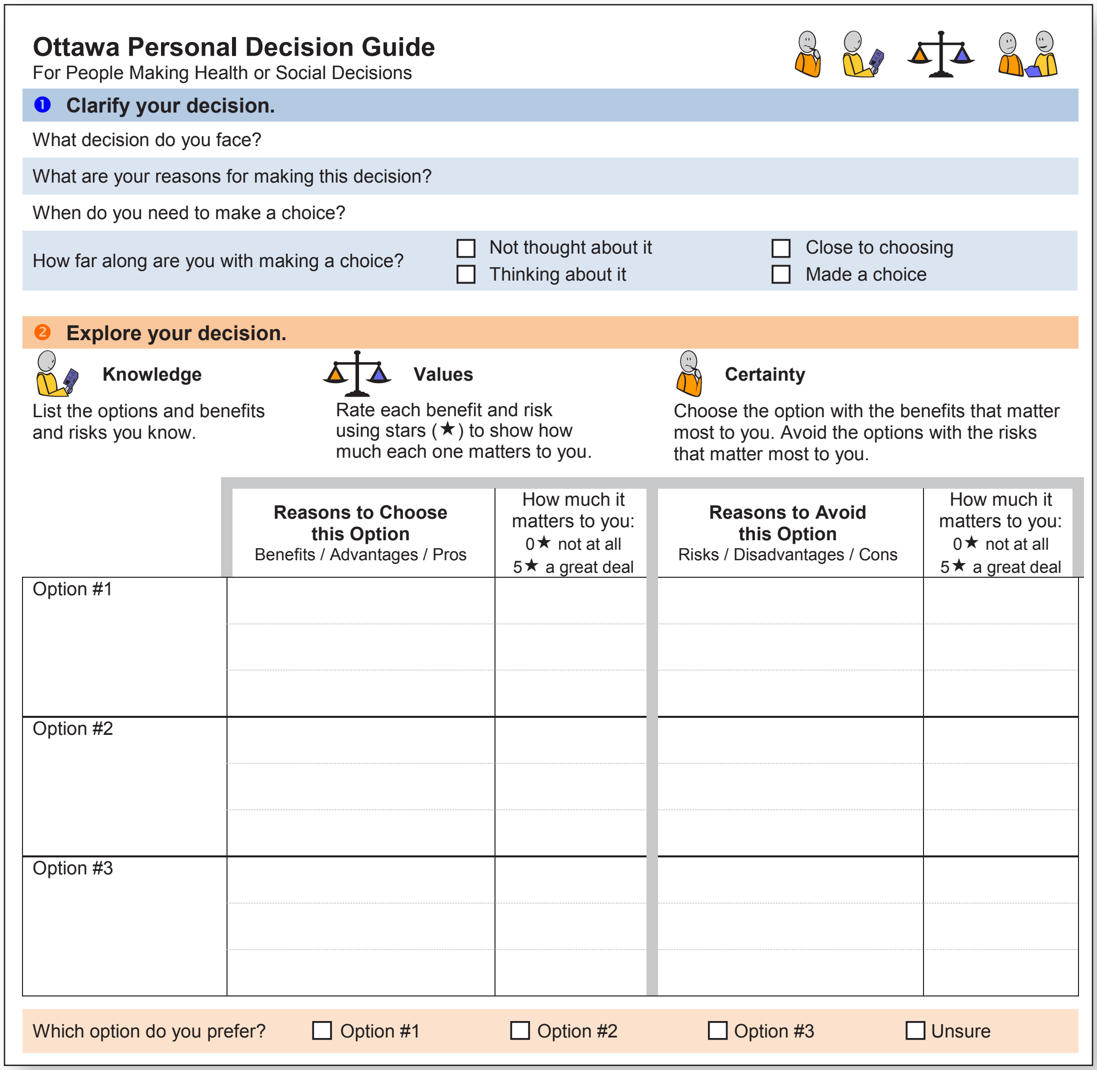
Patients diagnosed less than six months ago put more emphasis on their quality of life, and they were more likely to say they would stop treatment due to side effects that negatively impact their quality of life. This may be because patients in early treatment are more worried about treatment-related side effects compared to those who have been living with the disease and know better what to expect.

USE DECISION AIDS

Patient decision aids are evidence-based tools designed to help patients effectively engage with their care teams to make treatment decisions together. These aids tend to be interactive and help providers guide conversations with patients, explain the decisions to be made, and elicit a patient's values and preferences regarding different treatment options.[12]

Decision aids often include information about the options being considered, diagrams showing outcome statistics for different options, and questions to prompt conversation about considerations that are important to the patient. Research has shown that when a decision aid is used to guide a conversation with a patient, patients are better prepared to make decisions and experience less decisional regret, an important outcome, since decisional regret is common among patients with prostate cancer.[13]

While there are patient decision aids for prostate cancer screening and early-stage treatment decision-making, there are currently no validated decision aids for patients with advanced prostate cancer. Researchers at the University of Virginia are attempting to fill that gap by developing and testing an interactive decision aid for patients with metastatic prostate cancer. This aid, called DecisionKEYS for Balancing Choices, was initially developed in 2005 and was tested for feasibility and acceptability on patients with breast cancer, advanced prostate cancer, and advanced lung cancer.[14] In more recent research using this decision aid, patients with advanced prostate cancer indicated that it helped them understand their treatment options.[8] With regard to factors important in decision-making, these patients reported that quality of life was more important than quantity of life and confirmed that contact with their care providers significantly influenced their decisions. Participants also said that using the decision aid helped them have more meaningful conversations with their healthcare providers.



Ottawa Personal Decision Guide

For People Making Health or Social Decisions

❶ Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice? ☐ Not thought about it ☐ Thinking about it ☐ Close to choosing ☐ Made a choice

❷ Explore your decision.

Knowledge
List the options and benefits and risks you know.

Values
Rate each benefit and risk using stars (★) to show how much each one matters to you.

Certainty
Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	**Reasons to Avoid this Option** Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer? ☐ Option #1 ☐ Option #2 ☐ Option #3 ☐ Unsure

Download full guide here: https://decisionaid.ohri.ca/decguide.html

While patients with early-stage diagnoses often have peers with whom they can discuss treatment options, patients with advanced prostate cancer may not have those connections to help them make treatment decisions.[10] When patients with metastatic prostate cancer do not have peers with similar experiences, including patient stories in decision aids may be helpful. Stories can be in written or video formats and outline the decision-making process for several patients who had to make a similar decision but chose different options.

CONSIDER HEALTH DISPARITIES

Teasing apart the impact of social determinants of health on incidence, mortality, and treatment in prostate cancer is challenging. Numerous studies indicate that prostate cancer incidence and mortality is significantly higher for Black Americans than for all other races. When adjusted for socioeconomic variables, the racial disparity decreases.[15]

RACE AND ETHNICITY

Nationally, prostate cancer incidence for Black individuals is significantly higher than for all other races. The incidence per 100,000 people is 171.6 in the Black population, compared to 97.7 for non-Hispanic White populations. Asian/Pacific Islanders have the lowest incidence rate at 53.9. Prostate cancer mortality per 100,000 people is also higher in the Black community, in which it is 38.3, compared to 17.9 in the non-Hispanic White community.[1]

The reason for this higher incidence and mortality of prostate cancer among Black people is likely due to a combination of genetic, social, and psychological factors. Also, prostate cancer risk appears to have a genetic component in people with West-African ancestry.[16] This genetic component is described in recent research, which highlights the link between androgen receptor pathways, EGFR expression, and other genetic predispositions that Black people have to the incidence of prostate cancer.[17]

Race can also influence treatment decisions. Black patients are more likely than other racial groups to make treatment decisions with a family member, an important nuance for providers to consider.[18] When compared to White patients, Black patients were more likely to have incorrect perceptions of the aggressiveness of their cancer.[19] This impacts treatment decision-making and could indicate an opportunity to decrease race-related disparities by improving patient education and communication, particularly through decision aids.

ACCESS TO CARE

Insurance status is clearly linked to stage of diagnosis, with uninsured patients more likely to present with advanced prostate cancer compared to insured patients. A study of Surveillance, Epidemiology, and End Results (SEER) data on individuals diagnosed with prostate cancer between 2007-2010 showed that White patients were more likely to be insured than non-White patients. Uninsured patients are also more likely to come from rural areas and have lower income and education levels.[20]

Access to care and standardized treatment using clinical guidelines are both critical factors to overcoming the disparity in prostate cancer mortality between Black and White patients. In one study, researchers compared three cohorts of patients with non-distant metastatic prostate cancer (meaning any size tumor, but only local lymph node involvement). SEER data represented the expected estimates of disparities, data from five regional VA Medical Centers represented patients with equal access to care, and data from a clinical trial represented patients with standardized treatment approaches and follow up. Black patients who were treated at a VA Medical Center or were treated in a clinical trial had similar outcomes to White patients. But in the SEER cohort in which equal access and standardization were not present, Black patients experienced an increase in prostate cancer-specific mortality compared to White patients, even after adjusting for other factors.[21]

SOCIOECONOMIC FACTORS

Care access and socioeconomic status have both been linked to poorer outcomes for patients with prostate cancer. Even in areas of the U.S. that are less racially diverse, the connection between socioeconomic factors, healthcare access, and increased prostate cancer mortality is strong. For example, 95 percent of people living in Appalachian Kentucky and 82 percent living in non-Appalachian Kentucky identify as White.[22] Researchers reported that while the incidence of prostate cancer in Appalachian Kentucky was lower than in non-Appalachian Kentucky, prostate cancer mortality rates in Appalachian Kentucky are higher, and patients are more likely to present with advanced prostate cancer.

The disparities between these two White populations are likely due to higher poverty rates, lower levels of education, and a higher percentage of comorbidities in the Appalachian population. Appalachian Kentuckians also had poorer access to healthcare compared to non-Appalachians. These social determinants of health are consistent with those that divide Black and White populations.[15]

Social determinants of health have also been linked to the number of prostate cancer treatment choices made available to patients. For example, researchers looked at differences in patients undergoing surgical versus medical androgen deprivation therapy (ADT).[23] While these two methods of treatment have similar clinical outcomes, there are significant differences in cost and quality-of-life factors. Medical ADT is more expensive and requires more intense clinical follow up, but it is reversible and has less of a negative impact on a patient's quality of life compared to surgical ADT.

Patients were more likely to receive surgical ADT if they came from lower socioeconomic levels, had Medicaid or public insurance coverage, or lived in rural service areas. Hispanic patients were more likely to receive surgical ADT, Black patients were equally likely to receive surgical or medical ADT, and White patients were more likely to receive medical ADT. Patients receiving treatment at NCI-designated cancer centers had lower rates of surgical ADT, regardless of the other factors mentioned.

MARITAL STATUS

Unmarried patients were more likely to undergo surgical ADT compared to medical ADT as well.[23] This is not the only evidence of prostate cancer disparities between married/partnered and unmarried/unpartnered patients. Other studies have linked marital status to prostate cancer survival, hypothesizing that patients with a spouse or partner may practice healthier behaviors and have better psychosocial support, which may lead to better survival outcomes.[24] This is an area with minimal research, but it may indicate an opportunity for identifying unmet patient needs and opportunities to intervene.

THE IMPACT OF COVID-19 ON CARE DECISIONS

Access to care and financial toxicity are important factors in decision-making, and 2020 heightened the role of both. The onset of the COVID-19 pandemic in early March 2020 impacted timely diagnosis and care across the entire U.S. healthcare system. The American Cancer Society reported that preventive cancer screening rates dropped dramatically in March and April.[1] By June, screening was returning, but was still below normal rates. Jamie Bearse, the CEO and president of the advocacy group ZERO, commented, "Men didn't need another reason to avoid the doctor in 2020, but unfortunately, COVID-19 gave them one."[2]

In addition, less medical testing, delays in certain services for people in active treatment, and reduced access to clinical trials due to the suspension of enrollment will likely impact patient outcomes for years to come. The increase in financial toxicity due to loss of jobs and health insurance could also impact outcomes. Even when a privately insured patient is diagnosed early, estimated out-of-pocket costs for prostate cancer surgery are close to $4,000.[25] For households experiencing pandemic-related financial instability, these costs may influence treatment decision-making.

CONCLUSION

Current research points to a wide range of patient characteristics that clinicians should consider when tailoring their approach to decision-making. Patients express different preferences and values depending on their age, race, marital/partner status, socioeconomic status, and overall health. Because many of these variables are also connected to treatment disparities, crafting decision aids across all patient populations is important.

For additional resources from this ACCC education program, Comprehensive Care of Patients with Advanced Prostate Cancer through Shared Decision-Making, please visit accc-cancer.org/advanced-prostate-SDM.

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