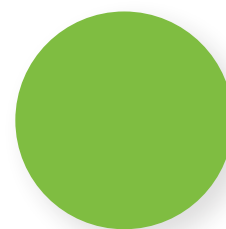


Patient Navigation in Cancer Care 2.0
Guiding patients to quality outcomes™

Navigating Advanced Prostate Cancer

A Resource Guide for the Navigator



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Lillie D. Shockney, RN, BS, MAS, HON-ONN-CG

University Distinguished Service Professor of Breast Cancer
Professor of Surgery
Johns Hopkins University School of Medicine
Co-Developer and Faculty Advisor of Work Stride: Managing Cancer at Work
Co-Founder, AONN+
Baltimore, MD

Lani Bradish, BSN, RN, OCN, GU

Oncology Nurse Navigator
University of California San Francisco
San Francisco, CA

Marco Carlos, OPN-CG

Oncology Patient Navigator
Urology Austin
Austin, TX

Frank dela Rama, RN, MSN, AOCNS, AGN-BC

Prostate Cancer Nurse Navigator
Sutter Health - Palo Alto Medical Foundation
Palo Alto, CA

Danelle Johnston, MSN, RN, HON-ONN-CG, OCN

Chief Nursing Officer
Senior Director of Strategic Planning and Initiatives
The Lynx Group
Austin, TX

Brigid Miralda, RN, MSN, FNP

GU Oncology Nurse Navigator
University of California San Francisco
San Francisco, CA

Wendy Poage, MHA

President
Prostate Conditions Education Council
Centennial, CO

Chuck Strand

Chief Executive Officer
US TOO International
Des Plaines, IL



ACADEMY OF ONCOLOGY NURSE & PATIENT NAVIGATORS: MISSION AND VISION

The mission of the Academy of Oncology Nurse & Patient Navigators (AONN+) is to advance the role of patient navigation in cancer care and survivorship care planning by providing a network for collaboration and development of best practices for the improvement of patient access to care, evidence-based cancer treatment, and quality of life during and after cancer treatment. Cancer survivorship begins at the time of cancer diagnosis. One-on-one patient navigation should occur simultaneously with diagnosis and be proactive in minimizing the impact treatment can have on quality of life. In addition, navigation should encompass community outreach to raise awareness targeted toward prevention and early diagnosis, and must encompass short-term survivorship care, including transitioning survivors efficiently and effectively under the care of their community providers.

The vision of AONN+ is to increase the role of and access to skilled and experienced oncology nurse and patient navigators so that all patients with cancer may benefit from their guidance, insight, and personal advocacy.



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PFIZER ONCOLOGY: OUR COMMITMENT

Pfizer Oncology is a committed partner in the cancer care community, dedicated to humanity's quest for longer, healthier, happier lives. Our goal is to improve the life of every patient with cancer and positively impact all who deal with this disease. One way we demonstrate our commitment to this goal is through our support of the patient navigation movement occurring throughout the United States.

Ask your Pfizer Oncology Account Manager about *Patient Navigation in Cancer Care 2.0* to support your commitment to making a difference in the lives of patients and in shaping the future of cancer care. Additional information regarding this program can be found at www.patientnavigation.com.



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I. INTRODUCTION & FOUNDATIONS IN PROSTATE CANCER

The prostate cancer landscape is broader than ever before, amplifying the challenges for not only the patients facing the disease, but also their families and/or caregivers. Nurse and patient navigators are in a prime position to help these individuals maneuver through and overcome those challenges, which can vary greatly—from patient-centered issues in clinical decision-making and psychosocial issues to system-wide issues in healthcare delivery and health status disparities. Patients with prostate cancer may encounter navigators in a variety of settings, including academic and community-based cancer centers, as well as in private practice clinics in urology, medical, and radiation oncology. Regardless of the setting, common goals still center on optimizing patient outcomes and reducing barriers to care.

In prostate cancer care, the navigators themselves differ in the scope of services they provide, with some focusing exclusively on prostate cancer, and others serving multiple cancer types. Navigator roles have also been further delineated into localized versus advanced prostate cancers. Some navigators may have a longitudinal relationship with the patient, spanning from initial diagnosis through treatment and into follow-up. Other robust programs may have navigators for each step in the care continuum, coordinating handoffs at each care transition. Given this variety, some navigators may meet multiple new patients with prostate cancer in 1 day, whereas others may only meet 1 new patient sporadically over the span of weeks or even months. Therefore, the toolkit presented here provides a centralized set of resources and offers guidance to navigators on how to best serve those patients and their families/caregivers who are facing the disease, particularly in the advanced stages.

In recent years, treatment choices for advanced prostate cancer have multiplied, with care plans becoming increasingly complex.¹ Navigators are now dealing with issues that were rare or nonexistent in years past, so keeping current with the ever-changing landscape of advanced prostate cancer is key to the role. Tools for clinical assessment of types of advanced prostate cancer include conventional blood tests (mainly prostate-specific antigen [PSA]) and a growing array of imaging modalities, as well as germline and tissue-based genetic testing and analysis, yet current controversies and limitations exist for many of these tools.^{2,3} Even with standardized guidelines for treatment, multiple pathways exist for patients with advanced prostate cancer with similar clinical stage and grade, causing decision-making for both patients and healthcare providers to be progressively challenging.⁴ Developing a working knowledge of the clinical aspects of advanced prostate cancer is the first step for navigators fostering their practice in the field.

This toolkit includes:

- An overview of advanced prostate cancer
- Facts about prognosis, treatment pathways, and side effects
- A model of navigation for advanced prostate cancer
- Definition of goals of treatment/care
- Strategies for shared decision-making
- Communication tips for navigator/patient/caregiver
- Communication tips for within the multidisciplinary team
- Methods for overcoming barriers to care
- Review of factors causing distress specific to patients with advanced prostate cancer
- Discussion of palliative care versus end-of-life care
- Resources for navigators, patients, and families/caregivers

Foundations in Prostate Cancer: Clinical and Pathologic Features

An initial diagnosis of prostate cancer is often triggered by an elevated PSA level, which leads to a DRE and potentially a prostate biopsy, with microscopic analysis of tissue. A substantial amount of time may have passed between initial diagnosis and biopsy for some patients with advanced prostate cancer, who may have been previously classified with only localized, low- to intermediate-risk disease, and may have received localized treatment at that time. Physical symptoms usually trigger a new staging workup. One may have bone pains, burning urination to flag workup, which results in confirmation of metastatic disease. Other patients may present with advanced-stage disease, which is only revealed by symptoms and captured by imaging. Once identified, risk stratification based on clinical findings can help determine potential clinical pathways. Within their appropriate scope of practice, navigators can collaborate with patients and healthcare providers to move toward the optimal care plan. Understanding the clinical landscape of advanced prostate cancer helps navigators to best strategize their supportive care, counseling, and education of the patient.

Understanding the clinical landscape of advanced prostate cancer helps navigators to best strategize their supportive care, counseling, and education of the patient.

Prostate Cancer Overview

Statistics, facts, and figures. Prostate cancer is the most common type of noncutaneous cancer found in men, with an estimated 174,650 new cases projected in the United States for 2019.⁵ Second only to lung cancer, the

estimated number of prostate cancer–related deaths for 2019 is expected to be 31,620, comprising approximately 10% of all estimated deaths from cancer in any site.⁶ Focusing on ethnicity, African-American men have had the highest prostate cancer mortality rates, considerably higher than in Caucasians, followed by Hispanics, Asian/Pacific Islanders, and lastly, East/Southeast/South Central Asian men.⁷ Local and regional stages make up the vast majority of prostate cancer found, and their 5-year relative survival rate is nearly 100%. For metastatic advanced prostate cancer, also known as distant-stage disease, the 5-year relative survival is 30%.⁶ Overall, prostate cancer incidence rates have shown a steady decline of approximately 6.5% per year since 2007, yet the incidence of distant-stage disease has increased from 2010 to 2014.⁸

Clinical Landscape

Newly diagnosed/localized versus advanced. Many navigators frequently have their first encounter with patients soon after a positive biopsy showing localized disease.⁹ Ideally, a long-term relationship has already been developed between the navigator and the patient with prostate cancer well before advanced disease occurs. Conversely, navigators may be introduced to patients after advanced disease becomes evident. Regardless of the initial presentation, navigators best serve these patients when their own knowledge is founded on a firm understanding of the full spectrum of prostate cancer, from localized through advanced disease.

Foundations in Prostate Cancer: Advanced Prostate Cancer Defined

Although there is not a universally accepted definition of advanced prostate cancer, for our purposes here, we will define it as when there is any concrete evidence of disease outside of the prostate organ itself. From the perspective of a focused navigation program, advanced prostate cancer can best be defined by disease that has migrated beyond the prostate itself into distant lymph nodes, or with metastases in the bone or viscera. The details of staging and risk stratification are covered in the text that follows.

Although there are many complexities to clinical staging and risk stratification, prostate cancer can initially be classified into 2 main categories—localized and advanced—prompting the navigator to emphasize distinct sets of care plans and overall goals. For clinically localized prostate cancer, the goal of treatment can be labeled as curative, or more specifically, matching treatment plans to patients who are most likely to benefit, while minimizing complications, so that they ideally never need repeat treatments.¹⁰ Options here conventionally include watchful waiting/active surveillance, surgery, radiation, and hormonal/androgen-deprivation therapy (ADT), as well as combination/multimodality therapies. Although both active surveillance and watchful waiting/observation generally monitor patients every 6 months (or sometimes more frequently), an important distinction is that periodic biopsies may be involved in active surveillance.¹¹ Typically, any sign of progression will lead to potentially curative treatment in active surveillance patients, whereas with observation, the next step is usually palliative in nature.

For advanced prostate cancer, the goal of treatment is labeled as palliative, as opposed to curative. Treatment plans are aimed at slowing progression of the disease and maintaining quality of life, within the scope of an irreversible disease, where repeat treatments are expected to slow progression. Here, successive rounds of anticancer treatments are given to the patient, continuing until disease progression or unacceptable tolerability. The mission is to control the cancer while still preserving quality of life for as long as possible. Given current and emerging technologies, patients with advanced prostate cancer can participate in palliative treatments from months to multiple years.¹² By helping patients and their families form a basic understanding of the goals and scope of treatment for advanced prostate cancer, navigators can have a positive impact on quality of life, specifically with defining expectations and visualizing the clinical pathways available to reach individualized goals. The shared experience is one of the most valuable contributions that navigators bring to the table, either gathered from their long experience in dealing directly with many patients diagnosed with advanced prostate cancer or through learning from their

colleagues in healthcare. For patients who are newly diagnosed with advanced prostate cancer, this is their first time experiencing the situation, whereas navigators may have virtually shared this experience with a multitude of patients and their families, which allows them to provide invaluable support.

Issues in PSA testing. PSA is a protein normally produced by the cells of the prostate gland but is also increasingly produced if these cells become malignant. Measuring serum blood levels of PSA, reported as nanograms per milliliter, was first approved by the US Food and Drug Administration in 1986 to monitor the progression of prostate cancer in patients already diagnosed with the disease.¹³ PSA levels can also rise as a result of benign conditions, including prostatitis and benign prostatic hyperplasia. Because of this overlap, it was originally believed that PSA testing could not be utilized for early detection, until a landmark 1991 study published by William Catalona and colleagues showed that PSA could be used as a first-line prostate cancer screening test even without suspicious findings on physical examination with digital rectal examination.¹⁴ Since then, the use of PSA testing in prostate cancer has not been without

PSA levels should not be the sole factor used to determine changes to the treatment plan, but rather, are assessed in conjunction with imaging, symptom review, and potentially, other laboratory tests.

controversy, and Dr Catalona himself recently offered a retrospective review of distinct eras in PSA use (Table 1), providing navigators with a historical perspective to help frame discussions with patients and their families about PSA testing.¹⁵

For patients already diagnosed with prostate cancer, including advanced disease, PSA testing to monitor outcomes

also carries similar controversies. Even before starting treatment, patients may benefit greatly by knowing what the clinician expects the PSA levels to be during and after treatment, and what levels may cause concern or necessitate additional follow-up treatment. PSA levels can fluctuate and may not always correspond with what the cancer is doing. Treatments for advanced prostate cancer often lower the PSA level initially, although sometimes, treatments may just prevent these levels from rising more, or even slow the rise.¹⁶ Therefore, PSA levels should not be the sole factor used to determine changes to the treatment plan, but rather, are assessed in conjunction with imaging, symptom review, and potentially, other laboratory tests. Far from a simple blood test, interpreting PSA can be very complex, and for patients with prostate cancer, even small changes in these levels can lead to stress and anxiety. Through education and support, navigators can help patients best place PSA testing into the proper context, given their current clinical picture.

Disparities in the population of patients with advanced prostate cancer. Harold P. Freeman, MD, founding father of patient navigation in cancer care, succinctly identified health disparities that patients might encounter over the care continuum, causing them to appeal to the navigator for help. Disparities can occur when useful therapeutic or medical interventions are not shared by all parties involved. In addition, health disparities generally arise from a complex interplay of economic, social, and cultural factors that can involve overlapping elements of poverty, social injustice, and relevant customs/traditions as principal causes. These causal factors can have an impact on all phases of the healthcare continuum—from prevention, detection, diagnosis, treatment, and survival to the end of life. Disparities tend to occur among those who experience 1 or more circumstances, such as insufficient resources, risk-promoting lifestyle and behavior, and social inequities. These factors must be taken into consideration when seeking to reduce or eliminate disparities.¹⁷

Health disparities are often perceived as those related to race and ethnicity, yet other classifications can cause inequities as well, including disability, gender/sexual identity, geographic location, income, education, and others.¹⁸ Prostate cancer has its own unique risk profile, with well-documented disparity related to race and ethnicity, notably among African-American men.¹⁹ One in 7 African-American men will be diagnosed

TABLE 1. Eras of Prostate-Specific Antigen Screening

Era	Synopsis	Selected milestones	Controversies/underlying issues
The Pre-PSA Screening Era (1930s-1991)	In the 6 decades before the PSA screening era, death rates progressively increased, because more men lived long enough to succumb to the disease. Most patients were diagnosed with incurable disease. For those who did not die of other causes within 15 years, many died of PCa	1991: Catalona et al showed that PSA could be used as a first-line screening test, without suspicious DRE findings	
The PSA Screening Era (1991-2008)	With the advent of PSA screening, there was a dramatic stage migration with most patients being diagnosed with curable disease. Thus, patients could elect treatment or observation, or they could opt not to have PSA testing and run the risk of later being diagnosed with incurable PCa	1994: FDA approved PSA testing as an aid to early PCa detection, in support of biopsy for PSA at ≥ 4.0 ng/mL	Some poorly differentiated or neuroendocrine PCa do not produce much PSA, reducing the value of PSA as a biomarker for these types of cancers
The PSA Prohibition Era (2008-2017)	Following USPSTF's recommendation, significantly reduced overall PCa incidence rates and precluded early PCa detection in many patients	2008: USPSTF issued a Grade D recommendation against screening men >75 years old ^a	Beginning with the 2008 recommendation, in men ≥ 75 years old, there has been a reversal of the favorable tumor stage migration, and since 2011, among men >75 years old, there has been a significant increase in the proportion and the absolute number of men presenting with metastases at the time of diagnosis with a similar trend in younger men
PSA Screening Renaissance (2017-)	Although the 2017 USPSTF is a recommendation change, there is more progress to be made with respect to: (1) baseline testing in men in their 40s to assess future risk for life-threatening disease, (2) earlier testing of high-risk men, such as African Americans and men with a family history whose risk of metastatic and lethal PCa is greater, and (3) testing healthy men ≥ 70 years old who are also at higher risk for life-threatening PCa	2017: USPSTF revised its "Grade D" recommendation and issued a draft recommendation that clinicians inform men aged 55-69 years about the potential benefits and harms of PSA screening	<p>If a man asks his physician whether or not he should have a PSA test, the physician should encourage appropriate testing. Moreover, men in their 40s should be informed that baseline PSA testing in their 40s is the best way to assess their risk for subsequent life-threatening PCa, as those in the top 10% PSA levels for their age-group account for almost half of all PCa deaths up to 30 years later, and those with levels >1.0 ng/mL clearly warrant more careful monitoring</p> <p>Healthy men in their 70s should not be discouraged from being tested if their life expectancy is ≥ 10 years. Life expectancy at age 70 in the US is >15 years; therefore, some older men will benefit from early detection and treatment of a potentially aggressive tumor</p>

^aMedicare coverage, under the Affordable Care Act, does not fully cover services rated Grade D, requiring co-payment instead.

DRE indicates digital rectal examination; FDA, US Food and Drug Administration; PCa, prostate cancer; PSA, prostate-specific antigen; USPSTF, US Preventive Services Task Force.

Source: Catalona WJ. *Med Clin North Am.* 2018;102:199-214.

with prostate cancer in his lifetime, compared with 1 in 8 Caucasian men. In addition, from 2011 to 2015, the average annual incidence rate was 179 cases per 100,000 non-Hispanic African-American men, which is 76% higher than the rate in non-Hispanic white men. Ultimately, the prostate cancer–related death rate in non-Hispanic African-American men is 2.2 times higher than in non-Hispanic white men and is the highest death rate for the disease of any racial or ethnic group.¹⁹

In general, minority racial/ethnic groups in the United States are more likely to be poor and medically underserved, with little to no access to proper healthcare; these groups are less likely to have recommended cancer screening tests, and are therefore more likely to be diagnosed at initial presentation with advanced-stage cancer. These same groups may also see differing rates of behavioral risk factors for cancer, such as higher rates of tobacco use, physical inactivity, obesity, and excessive alcohol intake, as well as higher rates of exposure to environmental risk factors (eg, motor vehicle exhaust in dense urban neighborhoods).¹⁸

Apart from socioeconomic risk, all groups may still experience some disparities related to culture, including mistrust of the healthcare system, fatalistic attitudes about cancer, or apprehension/embarrassment regarding certain medical procedures. Geographic aspects can also play a part in the level of access to care. Participation in clinical trials is often low due to the disparities listed above, whether patients experience just 1 type or several in combination.¹⁸

Treatment patterns also exhibit differences with respect to race; for example, compared with white men, African-American men are more likely to be treated with radiation therapy or ADT than radical prostatectomy. They are also more likely to present with advanced disease, have different treatment regimens, have shorter progression-free survival following treatment, and experience more treatment-related side effects. In addition, among all groups of patients with high-risk prostate cancer reviewed, men with high socioeconomic status received more bone scans, had a higher likelihood of intent-to-treat, and were more likely to have surgery; overall mortality and prostate cancer–specific mortality were both lower in this group.²⁰

Conversation Points: How Navigators Can Best Talk to Patients/Caregivers About Advanced Prostate Cancer

Having a structured agenda for your first navigation visit with the patient with advanced prostate cancer can help keep the discussion on point during a potentially very stressful time. However, it is also important to ask plenty of open-ended questions while counseling the patient and the family, to gather clues as to what they might need physically, emotionally, socially, and practically. Components of the initial navigation visits should include the following⁹:

- An explanation of clinical staging and review of the pathology report
- Pertinent treatment options based on national guidelines
- Possible side effects and discussion of management with HCP
- Nomograms are predictive tools based on patient and disease characteristics
- A review of potential quality-of-life issues/National Comprehensive Cancer Network Distress Thermometer tool
- Shared decision-making tools/strategies
- Referrals to support services as appropriate (eg, social work, nutrition, genetics, psychiatry).

These could potentially be covered in 1 visit, or perhaps spread out over several visits/encounters, depending on the desired pace for patients and families.

The navigator can specifically address goals of care in building a professional, supportive relationship by asking the patient the following²¹:

- How much do you want to know about your cancer?

- What do you currently know about your cancer?
- Who do you want to include in discussions about your cancer and its treatment options?
- Do you want to have information written down by me regarding your cancer?
- Tell me what is important to you
- Tell me what you are hoping for
- Now tell me your understanding of your clinical situation.

The nurse navigator also should interview the patient to inquire about life goals and significant milestones that are important.

The nurse navigator also should interview the patient to inquire about life goals and significant milestones that are important. Life goals are those that are hoped to be achieved in the future, such as getting a big promotion, having a grandchild, etc. Milestones are those events that will be occurring while the patient is receiving treatment and need to be preserved by dovetailing the milestone event into the treatment-planning process. Some life goals may be achievable based on when they are anticipated to occur. Those anticipated in the next few years may be achievable; however, other goals extending further into the future may need to be discussed later and alternative ways developed to fulfill that life goal.

An example would be that the patient hopes to become a grandparent one day. Currently, none of his children are married or planning to start a family within the next 5 to 10 years. So when the patient's cancer progresses to the point that longevity is clearly limited, the navigator may suggest getting recordable children's books so that the patient can record his voice reading from these books for a future grandchild to hear their grandfather's voice and learn from family members about him. An example for an upcoming milestone happening in the months ahead might be that the patient's grandson is graduating from high school in 8 weeks. The treatment team, therefore, should factor this important event into the treatment-planning process by not starting a new chemotherapy agent right before this event, and instead begin the treatment a few days after the graduation has taken place.²¹

Foundations in Prostate Cancer: Tools for Clinical Assessment and Staging ***Laboratory Tests for Advanced Prostate Cancer***

For those already diagnosed with advanced prostate cancer, PSA blood levels are the main focus in monitoring for progression of the disease. The absolute value of the PSA, or perhaps the PSA doubling time, may be concerning enough for further tests to be done or for treatment regimens to be adjusted.¹⁶ For people on ADT, blood levels of testosterone may be monitored to help measure success of therapy. There are many variations of PSA testing available within the arena of biomarker testing/PSA derivatives and other checks, but most of these do not apply to patients who already have prostate cancer; rather, they are geared more toward those still considering screening biopsy in the first place. Although a review of these tests is beyond the scope of this toolkit, navigators may encounter patients asking about them, including free PSA, complexed PSA, and PSA density, as well as urine testing for prostate cancer antigen 3 (PCA3).

Besides PSA and testosterone levels, other laboratory tests may contribute to the care plan. A concern for those receiving ADT is bone health, and measurements of calcium and vitamin D levels can indicate if intake is enough or whether dietary changes or supplements are needed (under the guidance of a registered dietitian or the treating physician). This may also help measure the effectiveness of bone-modifying medications, such as denosumab and zoledronic acid. Laboratory tests in advanced prostate cancer only include a few routine markers, yet each can be crucial in determining whether the treatment or observation plan is on track, or if prompt adjustments are needed.

Gleason Score/ISUP Grade Groups

The Gleason scoring system is used widely for grading prostate cancer cells that are found by biopsy.²² Most people dealing with prostate cancer have already had an initial biopsy by transrectal ultrasound biopsy for the diagnosis of clinically localized prostate cancer, but biopsies in advanced prostate cancer may include those in the prostate bed (for post-surgical patients, if warranted) or metastatic lesions found on imaging. Gleason scoring is one of the core measures used in risk stratification and treatment planning. Each cancerous sample is assigned 2 Gleason grades by the pathologist; the primary grade is the most common type within the sample and the secondary grade is the next most common. On a scale of 1 to 5, cancer cells that are relatively well-differentiated receive a score of 1, whereas very abnormal cells are scored as high as 5. The Gleason score is the summation of the primary and secondary scores.²² The International Society of Urological Pathology (ISUP) grade groups have been used to help patients better understand their true risk level. See **Table 2** for a comparison of ISUP grade to Gleason scoring.^{22,24} **Figure 1** is an excellent example of patient education with a graphic representation of Gleason scoring.²²

Imaging

Imaging in advanced prostate cancer includes several modalities, with some focusing on the prostate organ and nearby soft tissue, whereas others are used to evaluate lymph nodes or bone metastases. **Table 3** contains an overview of commonly used imaging tests and their use in clinical practice, as well as relative advantages/disadvantages and other pertinent aspects that can be useful for the navigator to know.^{4,25,26}

Navigators should be knowledgeable on their facility's protocols in imaging, particularly regarding patient education centered around preparation for these examinations, and offer some foundational information to help patients understand imaging results as they are detailed by their treating physician and the oncology care team.

Prostate Cancer Genetics/Genomics

Cancer is, by nature, a genetic disease. An accumulation of mutations in any 1 cell can eventually lead to the uncontrolled proliferation of cells, forming cancerous tumors. These mutations can be acquired or somatic, having occurred randomly or as a result of external and environmental risk factors. Other mutations can be germline, having been inherited from previous generations; these mutations are present in every cell at birth. Prostate cancer has long been associated with somatic mutations, but in recent years, more attention has been given to germline mutations, which are now known to have some bearing on the disease. The types of genes affected give some insight into cancer risk for patients and families, and into the specific, targeted treatments that are becoming available in advanced prostate cancer.

Homologous DNA repair genes. Homologous DNA repair genes are essential to any cell, enabling them to respond to any undue

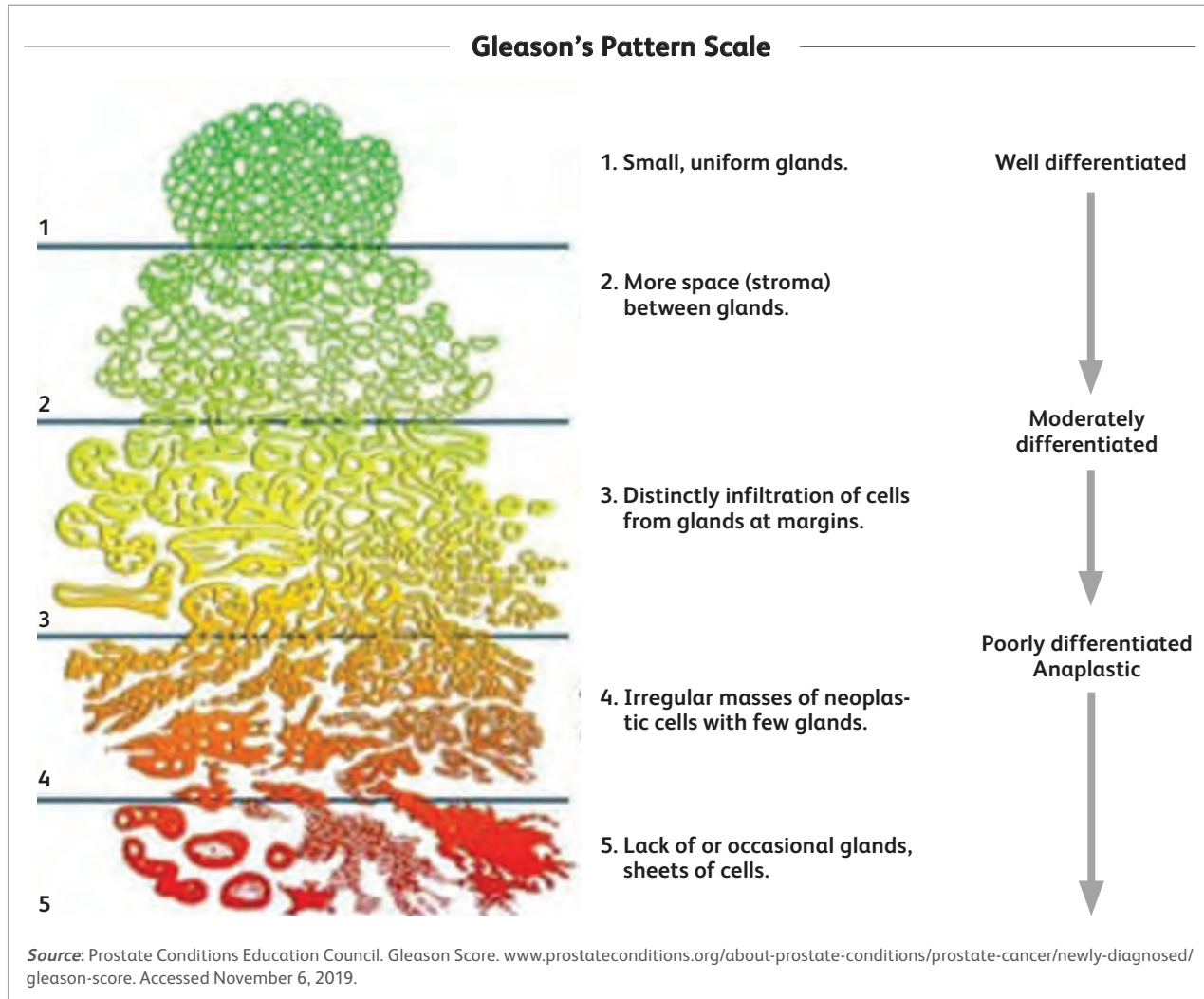
genetic changes that occur as cells divide and multiply. The *BRCA1* and *BRCA2* genes are included within this classification of genes, but also includes other genes that have an emerging association with prostate cancer, such as *ATM* and *CHEK2*. It is estimated that 20% to 25% of advanced prostate cancers will reveal

TABLE 2. Grade Group versus Gleason Score

Risk group	Grade group	Gleason score
Low	1	≤6
Intermediate favorable	2	7 (3+4)
Intermediate unfavorable	3	7 (4+3)
High	4	8
High	5	9-10

Source: The Prostate Cancer Foundation. Gleason Score and ISUP Grade Group. www.pcf.org/about-prostate-cancer/diagnosis-staging-prostate-cancer/gleason-score-isup-grade/. Accessed December 3, 2019. Used courtesy of the Prostate Cancer Foundation.

FIGURE 1. Prostate Conditions Education Council – Patient Guide to Gleason Score



either a germline (perhaps hereditary) or tissue (somatic) gene mutation.²⁷ These genomic findings can have important implications for treatment of advanced prostate cancer, as well as in cancer risk assessment for the patient and family.

DNA mismatch repair. Another group of genes relevant to prostate cancer are the DNA mismatch repair genes (*MLH1*, *MSH2*, *MSH6*, and *PMS2*), often associated with Lynch syndrome (also known as hereditary nonpolyposis colorectal cancer). All cells benefit from properly functioning DNA mismatch repair genes; mistakes in cell DNA replication can be exhibited as a “bump” in the double-stranded DNA. This bump is recognized by the protein products of the DNA mismatch repair genes and is then repaired as needed. Within tumors, somatic mutations in these genes lead to microsatellite instability (MSI) and deficient mismatch repair (dMMR). Tumors that are MSI-high or have dMMR status may be treated with appropriate targeted therapy; genetic counseling and testing, to assess for Lynch syndrome, is also recommended for these patients, potentially revealing risk in family members for colon and uterine cancers.⁴

For more information on homologous DNA repair genes and mismatch repair genes related to advanced prostate cancer, see *Section X of this toolkit*.

TABLE 3. Summary of Imaging Tests Used in Prostate Cancer

Imaging modality	Clinical usage	Relative sensitivity to bone vs soft tissue (selected modalities only)	Medicare coverage available?	Notes
Plain radiography	BONE: evaluate symptomatic regions in the skeleton			Not good for detecting early bone lesions; CT or MRI may be more useful to assess fracture risk
Ultrasound	SOFT TISSUE: used to guide transrectal biopsies of the prostate or prostate bed Initial detection and diagnosis			Standard ultrasound provides anatomic information Doppler ultrasound can allow assessment of vascular flow Limited tissue contrast between cancerous and benign tissue
Multiparametric prostate MRI	SOFT TISSUE/BONE: used to guide transrectal biopsies of prostate or prostate bed. Additional biopsies can be done on lesions detected by MRI, in addition to standard biopsies MRI with contrast allows for visualization of blood vessels also Initial detection and diagnosis, active surveillance			Excellent tissue contrast for identification of clinically significant prostate cancer Aids in detection of extracapsular extension Equivalent to CT for staging of pelvic lymph nodes Outperforms bone scan and targeted X-rays for detection of bone metastasis
Bone imaging/ bone scan	BONE: used to assess for metastatic disease to the skeleton Used in Unfavorable Intermediate Risk and higher for staging • Does not evaluate for osteoporosis; DEXA bone density scan would be used instead	Bone ++ Soft tissue -	Yes	Conventional bone scan uses technetium-99m-MDP
CT (CAT scan)	SOFT TISSUE: used to assess for nodal involvement or visceral metastases Used in Favorable Intermediate Risk and higher for staging if criterion met: Pelvic ± abdominal imaging recommended in nomogram predicts >10% lymph node involvement	Bone + Soft tissue ++	Yes	

(continued)

TABLE 3. Summary of Imaging Tests Used in Prostate Cancer (*continued*)

Imaging modality	Clinical usage	Relative sensitivity to bone vs soft tissue (selected modalities only)	Medicare coverage available?	Notes
PET-based scans	SOFT TISSUE/BONE: Used in evaluation for recurrence and metastatic spread			Combination scans PET/CT and PET/MRI available
	Not routinely used in staging	C-11 choline: Bone +++ Soft tissue +++	C-11 choline: Yes (limited)	Scans may differ based upon the type of tracer used: C-11 choline: may be used for detection of biochemically recurrent small-volume disease in soft tissues; may be used after bone scan for further evaluation of equivocal findings
	Used in advanced cancer clinical pathways, including:			
	• Radical prostatectomy persistence/recurrence	F-18 fluciclovine: Bone +++ Soft tissue +++	F-18 fluciclovine: Yes	F-18 fluciclovine: may be used for detection of biochemically recurrent small-volume disease in soft tissues; may be used after bone scan for further evaluation of equivocal findings
	• Radiation therapy recurrence			
• Monitoring for progression in metastatic disease	F-18 NaF: Bone +++ Soft tissue -	F-18 NaF: No	F-18 NaF: may be used after bone scan for further evaluation of equivocal findings	
		C-11 acetate: Bone: not evaluated Soft tissue: not evaluated	C-11 acetate: No	C-11 acetate: not yet FDA cleared; use only in clinical trial or registry
		Ga-68 PSMA: Bone ++++ Soft tissue ++++	Ga-68 PSMA: No	Ga-68 PSMA: not yet FDA cleared; use only in clinical trial or registry

CAT indicates computerized axial tomography; CT, computed tomography; DEXA, dual-energy x-ray absorptiometry; FDA, US Food and Drug Administration; MDP, methyl diphosphonate; MRI, magnetic resonance imaging; PET, positron emission tomography; PSMA, prostate-specific membrane antigen.

Sources: National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Prostate Cancer. Version 4.2019. www.nccn.org/professionals/physician_gls/pdf/prostate_blocks.pdf; Sakar S, Das S. *Biomed Eng Comput Biol*. 2016;7(Suppl 1):1-15; Koo PJ. Imaging controversies for localized and advanced prostate cancer. www.urotoday.com/journal/everyday-urology-oncology-insights/articles/107136-imaging-controversies-for-localized-and-advanced-prostate-cancer.html.

Foundations in Prostate Cancer: Clinical Synthesis

Navigators working with patients who have advanced prostate cancer must have a basic understanding of staging, including the TNM Staging System of the American Joint Committee on Cancer for prostate cancer.²³

Following proper staging and risk stratification, published treatment guidelines offer navigators a preview of what may happen moving forward for the patient newly diagnosed with advanced prostate cancer. Comprehending the foundations of prostate cancer—from staging and grading to the details revealed by laboratory testing, imaging, and genetics/genomics—allows navigators to synthesize the information and skillfully guide patients and their families through the care continuum for advanced prostate cancer.

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II. TREATMENT OF ADVANCED PROSTATE CANCER

Treatment: General Principles

The goals for treatment of advanced prostate cancer are much different from those for the treatment of localized disease, given that in patients with advanced disease, the cancer is now in distant lymph nodes and/or appears as metastases in the bone or viscera. In other cases of advanced prostate cancer, the patient's prostate-specific antigen (PSA) level continues to rise, even while receiving androgen-deprivation therapy (ADT), indicating that the treatment is no longer working and that the disease is now castrate-resistant.¹ At this stage, most cancers cannot be cured but are treatable. The goals of treatment are as follows: (1) to keep the cancer under control for as long as possible and (2) to improve a patient's quality of life to relieve any symptoms through palliation of disease.² Just as in other advanced cancers, these 2 goals overlap for people facing advanced prostate cancer, so the treatment choices must take into account the patient's quality of life, as well as personal preferences, based on values and lifestyle.³ Because of the overlap in these goals, the navigator and the primary oncology team can offer support through shared decision-making strategies, whereby patients, caregivers, physicians, and other members of the treatment team work together to make decisions regarding treatment, testing, and overall medical care. This process ensures that patient preferences and goals are incorporated when deciding the best options for each individual. In addition to considering the patient perspective and the cancer treatments themselves, we also need to evaluate any secondary comorbid conditions and how they might affect treatment decisions, as outlined in **Figure 1**.⁴

FIGURE 1. Ranked Severity of Comorbidities

RANKED SEVERITY OF COMORBIDITIES		
<p>Low comorbidity: Usually won't require adjusting cancer treatments. May include conditions like ulcers or rheumatologic diseases.</p>	<p>Moderate comorbidity: Conditions that may require the modification of cancer treatment. May include diabetes, vascular disease, paralysis, and AIDS.</p>	<p>Severe comorbidity: Illnesses that always require modifications of cancer treatment. May include diseases like COPD, liver dysfunction, dementia, and congestive heart failure.</p>
<p>AIDS indicates acquired immunodeficiency syndrome; COPD, chronic obstructive pulmonary disease. <i>Source:</i> Edwards BK, et al. <i>Cancer</i>. 2014;120:1290-1314.</p>		

Examples of shared decision-making tools and interventions are included in *Section III of this toolkit*.

Treatment Plan

Ideally, treatment of advanced prostate cancer is based on a comprehensive, patient-centered treatment plan. With the inclusion of representatives from urology and oncology, the multidisciplinary team reviews clinical findings from physical examinations, pathology, imaging, and laboratory tests (blood tests and tissue genomic tests, if available). PSA blood levels are routinely monitored

in people with prostate cancer. In this regard, perhaps even more important than the absolute PSA value is the PSA doubling time (PSADT), since it may influence which treatments are recommended and which treatments are not.⁵ For example, certain systemic therapies (eg, selected nonsteroidal anti-androgens) may be recommended for PSADT of ≤ 10 months, but perhaps not if the PSADT is longer than that.^{6,7} Genomic tests that analyze the genetic makeup of the cancerous tissue itself may reveal eligibility for the use of checkpoint inhibitors or even poly (ADP-ribose) polymerase (PARP) inhibitors within a clinical trial (refer to *Section X of this toolkit* for further details).

The patient-centered treatment plan summarizes the following:

- All key medical information about the patient (ie, overall health status; symptoms; physical changes; biopsy results [including pathologic and genomic features, if available]; imaging results [bone scan, computed tomography scan, and any advanced scans completed]; and laboratory tests)
- Quality-of-life and psychosocial assessments (ie, patient's limitations, concerns, preferences, and advance directives; financial stressors; and family/relationship status)
- Specific treatment objectives and care goals for the patient
- Individualize treatment to control advanced prostate cancer with anticancer drugs/radiation/surgery, including projected efficacy and toxicity profiles
- Individualized palliative care plan to relieve symptoms and suffering, and to enhance quality of life.

Overview of Treatment Types

Within the treatment plan, people with advanced prostate cancer often undergo multiple treatment modalities, either in sequence or in combination. The types of treatment modalities for advanced prostate cancer often include a selection of the following:

- Hormone management
- Radiation
- Immunotherapy
- Chemotherapy.

Navigators continue to provide support through education and shared decision-making interventions.

Each phase of treatment may be single-agent therapy or include a combination of modalities. Close monitoring after each phase of treatment, with imaging

and laboratory tests, ideally will not reveal any findings of concern, so people with advanced prostate cancer can have time periods without undergoing active treatment while experiencing an improved quality of life. With advanced prostate cancer, however, it is often just a matter of time until the next phase of treatment is needed. Treatment decision-making at each phase can create a new set of challenges, including response to prior treatments, the patient's status and any ongoing comorbidities, cross-resistance of some medications (eg, one agent may not work as well if another particular agent was given previously), and the evolution of the patient's treatment and care goals. Navigators continue to provide support through education and shared decision-making interventions.

Hormone Management

Testosterone and dihydrotestosterone, the most abundant androgens (ie, male sex hormones) in men, are normally produced in the testes and, to a lesser degree, in the adrenal glands. Although androgens are required for normal growth and function of the prostate gland, they are also necessary for prostate cancers to grow. ADT commonly uses medications to block the production or absorption of androgen hormones, which, in turn, inhibits tumor growth. The goal of treatment is to reduce circulating androgens to very low levels, thereby replicating the effect of a surgical castration or bilateral orchiectomy/removal of the testicles (which also remains as an available, but less often used, form of hormone management).^{1,8,9} There are 3 main categories of drugs used in ADT:

- **Androgen Receptor Inhibitors:** These agents act by inhibiting the androgen receptor, thus preventing the androgens from triggering the cancer cells to grow. Within this class of drugs, some agents are used when the prostate cancer is still castration-sensitive, whereas other, newer drugs in this class have demonstrated effectiveness even when the disease has become castration-resistant.^{1,8}

- **Luteinizing hormone–releasing hormone agonists and antagonists:** These agents act by lowering the amount of testosterone made by the testicles. Treatment with these drugs is sometimes called chemical castration, since they lower androgen levels just as well as does orchiectomy. Although these agents cost more than orchiectomy and require more frequent physician visits, most people select treatment with these medications rather than undergoing the surgical procedure.^{1,8}
- **Androgen Biosynthesis Inhibitors:** These agents act by lowering the production of androgen in the adrenal glands. Since these agents do not stop the testicle from producing testosterone, patients may also be taking luteinizing hormone–releasing hormone agonists or antagonists at the same time. Additionally, a side effect of androgen receptor inhibitors can include the lowering of other hormones in the body, such as cortisol, so patients also may need to take corticosteroid drugs during treatment with these medications.¹⁰

Radiation

Radiation therapy can be used to target the prostate gland or specific sites where the cancer has metastasized. For the earlier, localized stages of prostate cancer, radiation can be used instead of surgery, or perhaps after surgery, to treat the remaining cancer cells that were not destroyed, as evidenced by a detectable PSA level. Options include external beam radiation therapy (EBRT), brachytherapy (involves internal implantation of radioactive seeds), or a combination of both techniques.

In patients with advanced prostate cancer, the disease can metastasize to the bones, and radiation can be used to target these areas, particularly if pain is associated with the bones that now contain the metastatic disease.

In patients with advanced prostate cancer, the disease can metastasize to the bones, and radiation can be used to target these areas, particularly if pain is associated with the bones that now contain the metastatic disease. Various forms of EBRT are used, as brachytherapy is very rarely utilized in patients with advanced prostate cancer who have bone metastases. Although radiation therapy is not expected to eliminate all of the cancer cells in the bones, it can help relieve bone pain.² External radiation treatment is administered to the affected bone or area, usually with a series of daily treatments. The pain may lessen over subsequent days or weeks, and during this time, the pain may increase slightly before it actually decreases.¹

If several areas of symptomatic bone lesions exist and the metastatic disease is limited to the bone only, radionuclide therapy can be administered intravenously with a radioisotope, such as radium-223,¹¹⁻¹³ having received US Food and Drug Administration approval for this use in 2013.¹¹ Since radium and calcium have similar chemical properties, the radium accumulates in areas of bone that are rapidly growing, which is often in the bone metastases. These types of radiopharmaceuticals emit a powerful energy that helps to kill these cancer cells, but limits damage to nearby healthy cells and tissue.¹¹

Immunotherapy

The use of immunotherapy for the treatment of advanced prostate cancer stimulates one's own immune system to recognize and destroy cancer cells more effectively. Drug classes within this category that are used to treat patients with prostate cancer include personal autologous cellular immunotherapy and immune checkpoint inhibitors.

Personal Autologous Cellular Immunotherapy

This autologous cancer immunotherapy is manufactured from the patient's own white blood cells, which are collected through leukapheresis over a few hours. These cells are sent to a laboratory, where they are mixed with a protein from prostate cancer cells that is called prostatic acid phosphatase. This preparation

is then sent back to the physician's office or hospital for infusion back into the patient. This process is repeated 2 additional times, 2 weeks apart, for a total of 3 doses of cells. These cells help the other immune system cells attack the prostate cancer.^{15,16} Patients with advanced prostate cancer may be candidates for this type of treatment if their disease no longer responds to hormone treatment and they are still experiencing minimal to no symptoms.^{14,15}

Immune Checkpoint Inhibitors

Part of the function within the immune system involves its own ability to keep itself from attacking the body's normal cells. Checkpoint proteins on the immune cells act like switches to turn on (or off) an immune response. Since cancer cells can utilize immune checkpoints to prevent the immune system from attacking them, immune checkpoint inhibitors can be effective in boosting the immune response against prostate cancer cells.¹⁷ Programmed cell death protein 1 (PD-1) is a checkpoint protein that is found on the surface of immune system T-cells. Selected advanced

Patients who are receiving prolonged ADT or who have metastatic disease that has spread to the bone are at risk for fractures, particularly in the wrists, spine, and hips.

prostate cancers can be treated with a PD-1 inhibitor. If tissue analysis of the prostate cancer cells obtained on biopsy tests positive for specific gene changes, such as a high level of microsatellite instability or a deficiency in one of the mismatch repair genes, patients with advanced prostate cancer may be treated with this agent, which is usually administered as an intravenous infusion every 2 or 3 weeks.¹⁵

(See Section X of this toolkit for more details on the genetics/genomics of prostate cancer.)

Chemotherapy

Chemotherapy is used in patients with advanced prostate cancer that is no longer responsive to hormonal therapy or that has aggressively spread to bones and soft tissue within the abdominal cavity. In advanced prostate cancer, chemotherapy regimens most commonly use anticancer drugs within the taxane class.¹⁸ In rare subtypes of prostate cancer, such as small cell or neuroendocrine, platinum-based chemotherapies may be used.^{18,19} Typically, these agents are administered intravenously in cycles, with a rest period following each episode of treatment, to allow for some recovery from any side effects associated with use of the medication. Cycles are often 2 or 3 weeks in length, with schedules varying based on the drugs used and the patient's individual recovery time.²⁰

Optimizing Bone Health

Patients who are receiving prolonged ADT or who have metastatic disease that has spread to the bone are at risk for fractures, particularly in the wrists, spine, and hips. Older patients receiving ADT have significantly high rates of osteoporosis—that is, 50% at 4 years and 80% at 10 years. Bone metastases develop in 30% of patients with castration-resistant prostate cancer within 2 years of castrate resistance and in >90% over the course of the disease.^{21,22}

Bone-specific therapies are an important component of care for those with advanced prostate cancer and can decrease the risk for skeletal-related events. Prior to the initiation of ADT and reinforced throughout the treatment course, patient education should focus, in part, on optimizing bone health and minimizing fracture risk. A bone mineral density (dual-energy x-ray absorptiometry) scan should also be obtained as a baseline measure, with repeat scans performed to monitor patients. Weight-bearing exercise should be encouraged, in addition to smoking cessation and reduced alcohol use.

Bone-specific therapies can help increase bone mineral density and reduce fracture risk. These treatments are used to relieve bone pain, prevent fractures, and potentially decrease the need for radiation to the bones, as well as reduce the risk of spinal cord compression.²³

For patients receiving ADT or those with bone metastases, supplemental calcium and vitamin D can be an important adjunct to bone health, as well as a means of counteracting the lowered calcium levels associated with the use of bone-modifying agents. A physician or registered dietitian can best assess and advise patients by obtaining their laboratory test results and conducting a full dietary review.

Clinical Trials

During shared decision-making discussions, clinical trial participation should be considered as a potential option for patients with advanced prostate cancer. As of September 2019, the National Library of Medicine's site, ClinicalTrials.gov, lists more than 400 clinical trials on prostate cancer. Some of the tests and interventions under investigation include the following:

- Novel imaging agents and related hardware/software in positron emission tomography/magnetic resonance imaging
- PARP inhibitors
- Inhibitors of the PI3K pathway
- Inhibitors of DNA damage response
- Targeted alpha therapy
- Prostate-specific membrane antigen targeting approaches
- Molecular characterization of prostate cancer to aid in treatment decision-making.

Clinical trial participation provides patients with advanced prostate cancer access to advanced care practices, along with close monitoring by an extended healthcare team in addition to the primary oncology providers.

Clinical trial participation provides patients with advanced prostate cancer access to advanced care practices, along with close monitoring by an extended healthcare team in addition to the primary oncology providers. Along with the opportunities presented by clinical trials, challenges exist with respect to enrolling patients in these trials, as well as maintaining their participation. Navigators can play a key role in helping patients overcome any barriers to participation in clinical trials. They can also screen patients for clinical trials by comparing the clinical trial criteria to the patient's current and past medical history. Additionally, the timing of discussing clinical trials can influence a patient's willingness to join a trial. If the navigator knows the patient is very distressed on a particular day, that might not be the ideal

People with advanced prostate cancer may not present with any symptoms, with their cancer solely being identified and monitored with imaging and laboratory tests.

moment to have a long discussion about clinical trial enrollment, although the patient may be a candidate for such. Instead, the navigator can arrange to discuss the clinical trial opportunities at another time and engage the clinical trials nurse in meeting with the patient to discuss such a clinical opportunity (Tables 1 and 2).

Palliation/Relieving Symptoms of Advanced Prostate Cancer

People with advanced prostate cancer may not present with any symptoms, with their cancer solely being identified and monitored with imaging and laboratory tests. Treatment in these cases aims at slowing the

TABLE 1. Clinical Trials: Issues and Barriers That Confront Patients with Advanced Prostate Cancer

Type	Issues/barriers
Low enrollment	<ul style="list-style-type: none"> • 20% of all US patients with cancer are eligible for a clinical trial • Only 3% to 5% actually participate • Minority, rural, and elderly patients have especially low enrollment
Lack of understanding	<ul style="list-style-type: none"> • Patients and caregivers may be unsure about the process of trial enrollment and participation
Lack of effective decision-making	<ul style="list-style-type: none"> • Patients and caregivers may lack the ability to make an informed decision and give ongoing consent to a trial due to: <ul style="list-style-type: none"> — Literacy — Language barrier — Unrelieved distress — Lack of time — Lack of capacity (attributed to psychosocial/physical barriers such as lack of transportation or pain) — Misconceptions about the nature of trials
Financial/cost issues	<ul style="list-style-type: none"> • Patients have unanswered concerns about coverage for “usual care” costs apart from treatment and testing that is specific to the trial • Financial problems and their effects (lack of support network, food insecurity, etc), which raise fears of unexpected costs of participation
Healthcare team deficits in knowledge/time	<ul style="list-style-type: none"> • Busy professionals may not be up to date on available trials • Potential reasons include: <ul style="list-style-type: none"> — Lack of knowledge of the portfolio of trials available to patients — Time constraints for enrolling and managing the patient on a trial — Negative perceptions of clinical trials

Source: Pfizer. Metastatic breast cancer pathways: a resource guide for the navigator. January 2019. http://navigationroundtable.org/wp-content/uploads/metastatic_breast_cancer_manuscript_toc_link_04_03_19-1.pdf. Accessed November 6, 2019.

growth of the cancer to prevent and delay the patient’s symptoms from impacting quality of life. When symptoms arise, their type and severity depend on the size of the new growth and the location where the cancer has spread.²⁴ Clinicians have many forms of symptom management—referred to as palliation—to offer to patients with advanced prostate cancer. Palliation was once a term associated with end-of-life care, but that is no longer the case. Major oncology organizations now recommend that the physical, psychosocial, and spiritual comfort associated with palliation should be part of the care plan for all patients with advanced cancer. This recommendation is supported by clinical evidence from multiple studies.^{25,26}

Guidelines on Palliative Care

In 2017, the American Society of Clinical Oncology (ASCO) convened members of the ASCO Ad Hoc Palliative Care Expert Panel to develop a guideline update. The resulting publication, “Integration of Palliative Care into Standard Oncology Care,” states that patients with advanced cancer, such as metastatic breast cancer, should receive dedicated, interdisciplinary palliative care early on, while receiving treatment for their cancer. Essential components of palliative care include the following²⁶:

- Rapport and relationship-building with patients and caregivers
- Symptom, distress, and functional status management, such as pain, shortness of breath (dyspnea), fatigue, sleep disturbance, mood disorder, nausea, and constipation
- Exploration of understanding and education about disease and prognosis
- Clarification of treatment goals
- Assessment and support of coping skills

TABLE 2. Navigator Skills for Supporting Patients in Clinical Trial Participation

Class of skill	Navigators' skills/activities
Trial identification and enrollment	<ul style="list-style-type: none"> • Develop awareness of trials in APC through fact-finding and discussion with healthcare team members • Focus on educating and supporting patients on clinical trials, rather than pushing for enrollment • Provide population-appropriate peer support that encourages participation of racial/ethnic minorities and other underserved groups
Informed consent	<ul style="list-style-type: none"> • Present the trial option in a neutral way—do not “sell” the trial • View informed consent as a process • Emphasize patient’s right to decline/drop out • Identify and discuss with patient and caregiver any impediments to informed consent and decision-making • Learn the cancer center’s policies and procedures regarding informed consent • Offer support to patients who are considering withdrawing consent after initially consenting to participate; discuss reconsenting
Shared decision-making	<ul style="list-style-type: none"> • Facilitate ongoing patient education • Be aware of ethical issues and standards for clinical trials • Encourage patients to report concerns to healthcare team
Logistics	<ul style="list-style-type: none"> • Help the patient address issues that interfere with ongoing trial participation: <ul style="list-style-type: none"> — Coverage issues – Example: Work with patient, healthcare team, and cancer center financial staff to learn what the trial pays, what insurance pays, and which costs the patient pays — Transportation/lodging issues – Example: Help patient secure transportation or hotel — Distress/psychosocial issues – Examples: Involve social worker; connect patient with community resources that provide food, social interaction, housing • Literacy/language/cognitive issues – Examples: Identify translators; make reminder calls to patients for testing and treatment/post-visit calls
Communication	<ul style="list-style-type: none"> • Maintain open, regular communication among patient/caregiver/healthcare team • Reach out to healthcare team to obtain status updates on patients in trials^a • Encourage patients to communicate with the healthcare team regarding: <ul style="list-style-type: none"> — Adverse effects of treatment — Problems following the treatment/testing plan of the study — Problems remembering to take oral medication

APC indicates advanced prostate cancer.

^aWithin the parameters of the Health Insurance Portability and Accountability Act and the cancer center’s ethical standards for clinical trials.

Source: Pfizer. Metastatic breast cancer pathways: a resource guide for the navigator. January 2019. http://navigationroundtable.org/wp-content/uploads/metastatic_breast_cancer_manuscript_toc_link_04_03_19-1.pdf. Accessed November 6, 2019.

- Assistance with medical decision-making (ie, discussion of healthcare proxies and advance directives)
- Coordination with other care providers
- Provision of referrals to other care providers, as needed.

Please refer to Section XI for more details on palliative care.

Relieving Symptoms and Preserving Quality of Life

Development of symptoms in advanced prostate cancer can be related to local invasion of the tumor, metastasis to the bone/viscera, or, ultimately, to compression of the spinal cord. Metastases can commonly affect the quality of life of patients with advanced prostate cancer with specific symptoms, including the following²⁷:

- Lower urinary tract symptoms

- Lymphedema in node-positive advanced prostate cancer
- Ileus/constipation, due to local compression and obstruction of the rectum or concurrent use of opioid analgesics
- Neuropathy, due to tumor invasion or use of neurotoxic drugs (including taxanes)
- Pain caused by bone metastases
- Osteoporosis/bone loss/fracture risk.

Medication

Common methods to treat symptoms may include the following:

- Opioid and nonopioid analgesic medications may help relieve bone and other types of pain
- Adjuvant pain medications, including antidepressants and anticonvulsants, may help manage pain arising from nerve damage or sensitization (neuropathic pain)
- Medications to help optimize urinary flow
- Medications for the management of constipation
- Bone-specific therapies
- Other specific symptoms may be managed with medication at the clinician's discretion.

Integrative Care

Patients may also experience relief of pain, distress, and fatigue through the use of integrative therapies, which include, but are not limited to, the following:

- Massage (cancer massage by someone certified in this technique)
- Physical therapy (including pelvic muscle therapy to improve continence)
- Acupuncture
- Mindfulness practice
- Relaxation
- Yoga (gentle yoga)
- Cognitive behavioral therapy
- Reiki
- Counseling
- Support groups.

With a working knowledge of the treatment modalities used in patients with advanced prostate cancer, navigators can best guide patients and their families along these complex clinical pathways.

Conclusions

A wide variety of treatment modalities exist for patients with advanced prostate cancer, providing those who are facing the disease with multiple opportunities for continuing cancer control and optimizing their quality of life. Anticancer treatments are derived from a variety of categories: hormone management, radiation, immunotherapy, and chemotherapy. Maintaining bone health is key, given the increased risks for osteoporosis and skeletal-related events among those with the disease. Although clinical trials can offer patients access to emerging technologies in development, many barriers still exist with respect to obtaining this additional level of care. Palliative care is appropriate as soon as a diagnosis of advanced prostate cancer has been confirmed to best provide for symptom management and the smooth transition of care. With a working knowledge of the treatment modalities used in patients with advanced prostate cancer, navigators can best guide patients and their families along these complex clinical pathways.

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III. COMMUNICATION DURING TREATMENT

From diagnosis through staging and into determining the treatment plan, communication from the healthcare team to the patient with advanced prostate cancer and family members focuses mainly on education—feeling much like a crash course on the disease. From the patient’s perspective, communication is decidedly one way and demands that a considerable amount of information be absorbed in a short amount of time.

Compounding this stress, patients also are forced to accept the fact that this volume of information will have a very personal impact on quality of life—both for themselves and for their families.

Navigators have the unique opportunity to help open lines of communication among all who are involved in the care

of the patient—most importantly, to gain insight into how they are coping with the disease and their decision-making with respect to undergoing treatment. Open and collaborative communication can aid the navigator in identifying the needs of the patient, ranging from the purely clinical, to the psychosocial, emotional, and practical aspects of care. The barriers to care can then be more clearly recognized, encouraging patient-centered, as opposed to disease-focused, care.

Navigators have the unique opportunity to help open lines of communication among all who are involved in the care of the patient.

Dealing with a New Diagnosis of Advanced Prostate Cancer

Advanced prostate cancer is always an unwelcome surprise, regardless of whether the patient has a prior history of localized disease. Given the advanced technologies surrounding laboratory and imaging studies, people may even be asymptomatic at the time of an advanced prostate cancer diagnosis, which perhaps only is revealed because of a rising prostate-specific antigen level or incidental radiologic findings. Whereas early-stage or clinically localized treatment is focused on curative intent, treatment for advanced prostate cancer is focused on delaying tumor growth and on palliation. Palliation in cancer care is defined as the following:

“Relief of symptoms and suffering caused by cancer and other life-threatening diseases. Palliation helps a patient feel more comfortable and improves the quality of life, but does not cure the disease.”¹

Palliative care is one of the most misunderstood and underutilized therapies available for patients with cancer. It is best explained, however, as being quality-of-life preservation or quality-of-life restoration. Although palliative care is a component of hospice care, it also is a freestanding service that should be discussed and initiated as soon as a diagnosis of advanced prostate cancer has been rendered. A palliative care professional should be promptly added as a member of the patient’s multidisciplinary team. Upon learning that the therapies for advanced prostate cancer are palliative, as opposed to curative, people facing the disease can become frustrated at first, but they eventually may find comfort in the fact that treatment can continue in many different forms over several years. One way to explain it is to say, “The goal of treatment is to treat the cancer as a chronic illness, and to get it under control and keep it controlled for as long as possible, while maintaining your quality of life.” There are times when treatments are time-intensive, such as with daily external beam radiation therapy or periodic chemotherapy infusions. Breaks between certain treatment modalities, however, can be substantially long. In any case, there is a built-in requirement for a lifetime of watching and waiting with advanced prostate cancer, with patients always looking for the next test result to figure out when, not if, the next round of treatments will begin.

In support of overall quality of life, nurse navigators can ask certain questions to spark discussion and thought in the patient, which may help to best cope with this new diagnosis of advanced prostate cancer. One way to gauge the patient's current knowledge and degree of involvement in the decision-making process, as well as to learn more about the patient personally, can be achieved by asking the patient the "Navigator Questions: Building a Relationship with the Patient," as outlined in *Section I of this toolkit*. Open-ended questions such as these can help gain valuable insight into how the patient is handling the new diagnosis of advanced prostate cancer. The best, and often the most productive, patient encounters

TABLE 1. Recommended Sequence for Patient-Centered Medical Interviewing

Item	Suggested phrases/comments
Introduce and build rapport	All persons present at the visit should be introduced. In nonurgent situations, positive remarks about nonmedical issues, such as the weather, generalities about the day, or nonspecific encouraging observations, can help build rapport
Elicit the patient's agenda	Avoid starting with "How are you feeling?" or "How are you today?" because these questions may lead the patient to somatize his or her concerns into physical symptoms. Instead, use phrases such as "How may I help you today?" or "What can I do for you today?" to bring the focus to the purpose of the visit
List all of the patient's agenda items	Ask the patient, "Is there something else?" until he or she replies in the negative
Negotiate the agenda	Suggested phrases: "Which of these is the most concerning to you?" "I would also like to discuss your... today." "Because we have limited time, which of these problems would you like to discuss today?" "I know... it is important to you, and I am very concerned about your... Could we start with... first?"
Start discussing the patient's concerns with open-ended questions	Suggested phrases: "Tell me more about..." "Would you like to talk more about...?" "I want to know how it started..." "Tell me what the... was like?" "What else did you notice?"
Ask direct questions to elicit details about the chief concern, and perform a review of systems	Questions should address the duration, severity, and location of the problem; radiation and character of pain; relieving and aggravating factors; and any associated symptoms
Elicit the patient's perspective	See Table 2
Empathize	See Table 3
Summarize	Suggested phrases: "So, from what you have told me so far..." "Let me summarize what we have discussed so far." "You have told me a lot of things. Let me just say it out loud, so you know that I have heard you correctly."
Transition	Suggested phrases: "Now I would like to ask you some routine questions. These may seem personal or unrelated but are important for us to help you." "Now I would like to ask you some questions about your previous health."
Additional data	Elicit information about medicines and allergies, medical history, and social and family histories (including social support network, interests, and spirituality)

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flow more like a conversation, as opposed to a lecture. Asking open-ended questions can help navigators engage their patients in tackling the tough issues in advanced prostate cancer, while simultaneously gathering information about how they may be coping with the situation. Helpful advice from the medical literature on patient-centered communication, as outlined in **Tables 1-3**,² can help navigators hone their conversational skills in the healthcare arena.

Additionally, the nurse navigator needs to assess the patient and family for barriers to care and treatment. One of the most common barriers is lack of transportation, so it is reasonable to begin assessing the patient's needs for help with this issue. Financial barriers are

increasing drastically, with many patients having issues with copays and deductibles, with being unable to afford the drug therapies recommended, and even with expenses associated with medical supplies. It is always important to make patients feel comfortable discussing their specific needs, as well as to know how they measure their own quality of life. Patients also need the nurse navigator to be their advocate, speaking on their behalf when questions arise that the patient does not feel comfortable discussing with the treating physician but prefers, instead, to discuss with the nurse navigator. For example, the patient may have decided to stop treatment and engage in hospice care, but does not want to disappoint the physician by telling him that he wants to discontinue therapy. So being the patient's advocate is an essential role of the navigator in terms of communicating such information to the treatment team. Opening these lines of communication leads to more frequent assessment of patient needs, so we can adapt the plan of care and related interventions to best suit these patients and their families. Within every encounter with patients and families, active listening is critical for the navigator and can be initiated with some of the following techniques:

Set expectations from the onset of the meeting as to the purpose of the encounter, the anticipated duration, and what is expected to be accomplished.

- Ask the patient who should be present during the discussion
- Face the individual and have good eye contact
- Arrange the room so that you face the patient and others in attendance equally. This will ensure that everyone feels involved in the conversation
- Keep an open posture; avoid crossed arms or legs. Leaning slightly forward at times can help demonstrate active listening
- Pay attention to body language: Nurse navigators can learn so much through facial expressions, tone

TABLE 2. Phrases to Help Elicit the Patient's Perspective

Areas of focus	Suggested phrases
Feelings	"How did that make you feel [emotionally]?" "Tell me more about what was worrying you." "What were your emotions at that time?" "What would you say is worrying you the most?" "How do you feel about that?" "What was that like [emotionally]?"
Ideas	"What do you think is the cause of...?" "Do you have any thoughts on what might be causing this?"
Concerns	"What do you worry about regarding your health?" "Is there something you worry might happen?" "What are your fears about...?"
Impact	"How has your illness affected your daily life?" "What difficulties are you facing because of your illness?"
Expectations	"What would you like to get out of today's visit?" "What more can I do for you today?" "Is there anything else you need from us today?"

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of voice, gestures, and other nonverbal cues

- Try to minimize interruptions: A nurse navigator may often have many things to share with patients and families. But it is best to slow down and focus more on listening; a few seconds of silence can be greatly appreciated
- Ask questions: Based on what is heard from the patient and family, asking relevant questions can show that one is listening and can help clarify what has been said. Paraphrasing and summarizing are additional tools that the navigator can use in active listening
- Not all conversations take place in person. When assessing and communicating by phone, use a calm and warm voice. Listen carefully to the meaning behind the questions and clarify what you are hearing.

Planning for Treatment and Shared Decision-Making

Once a diagnosis of advanced prostate cancer has been established, treatment planning becomes the priority, as multiple clinical pathways are under consideration. When supporting patients through this decision-making process, it can be beneficial to ask how they usually go about making major life decisions. Do they like statistics? Do they prefer pictures or diagrams? Do they want to know the pros and cons of each option? What are their goals for care?

TABLE 3. Techniques for Expressing Empathy to Patients

Technique	Examples (may overlap)
Naming	<p>“It seems like you are feeling...”</p> <p>“I wonder if you are feeling...”</p> <p>“Some people would feel... in this situation.”</p> <p>“I can see that this makes you feel...”</p>
Understanding	<p>“I can understand how that might upset you.”</p> <p>“I can understand why you would be... given what you are going through.”</p> <p>“I can imagine what that would feel like.”</p> <p>“I can’t imagine what that would feel like!”</p> <p>“I know someone who had a similar experience. It is not easy.”</p> <p>“This has been a hard time for you.”</p> <p>“That makes sense to me.”</p>
Respecting	<p>“It must be a lot of stress to deal with...”</p> <p>“I respect your courage to keep a positive attitude in spite of your difficulties.”</p> <p>“You are a brave person.”</p> <p>“I am impressed by how well you handled this.”</p> <p>“It sounds like a lot to deal with.”</p> <p>“You have been going through a lot.”</p> <p>“You did the right thing by coming in.”</p>
Supporting	<p>“I want to help in any way I can.”</p> <p>“Please let me know if there is anything I can do to help.”</p> <p>“I am here to help you in any way I can.”</p> <p>“I will be with you in this difficult time.”</p> <p>“I will be with you all the way.”</p>
Exploring	<p>“Tell me more about what you were feeling when you were sick.”</p> <p>“How are you coping with this?”</p> <p>“What has happened since we last met?”</p>

Source: Hashim MJ. *Am Fam Physician*. 2017;95:29-34. Used with permission from Patient-Centered Communication: Basic Skills. January 1, 2017, Vol 95, No 1, American Family Physician. Copyright © 2017 American Academy of Family Physicians. All Rights Reserved.

Once a diagnosis of advanced prostate cancer has been established, treatment planning becomes the priority, as multiple clinical pathways are under consideration.

Shared decision-making (SDM) is a strategy that can improve the patient experience with making clinical decisions, and navigators can be instrumental in ensuring that SDM is part of the process. The overall objectives of SDM are met when (1) patients are fully informed of the treatment option and the trade-offs between risks and benefits, and

(2) patient values and preferences are incorporated into treatment decisions. The benefits of SDM are thought to be multifaceted. First, it fulfills the ethical responsibility of clinicians to facilitate patient autonomy in treatment decision-making, particularly because patients and their families are eventually subjected to the

outcomes of these decisions. Second, as patients become more engaged and informed, they are more likely to weigh the risks and benefits of treatment options. Lastly, evidence suggests that more informed, involved patients experience better psychosocial, and, in some instances physical, outcomes.³

S: Seek patient and caregiver participation

H: Help explore and compare treatment options

A: Assess patient values and preferences

R: Reach a decision with your patient

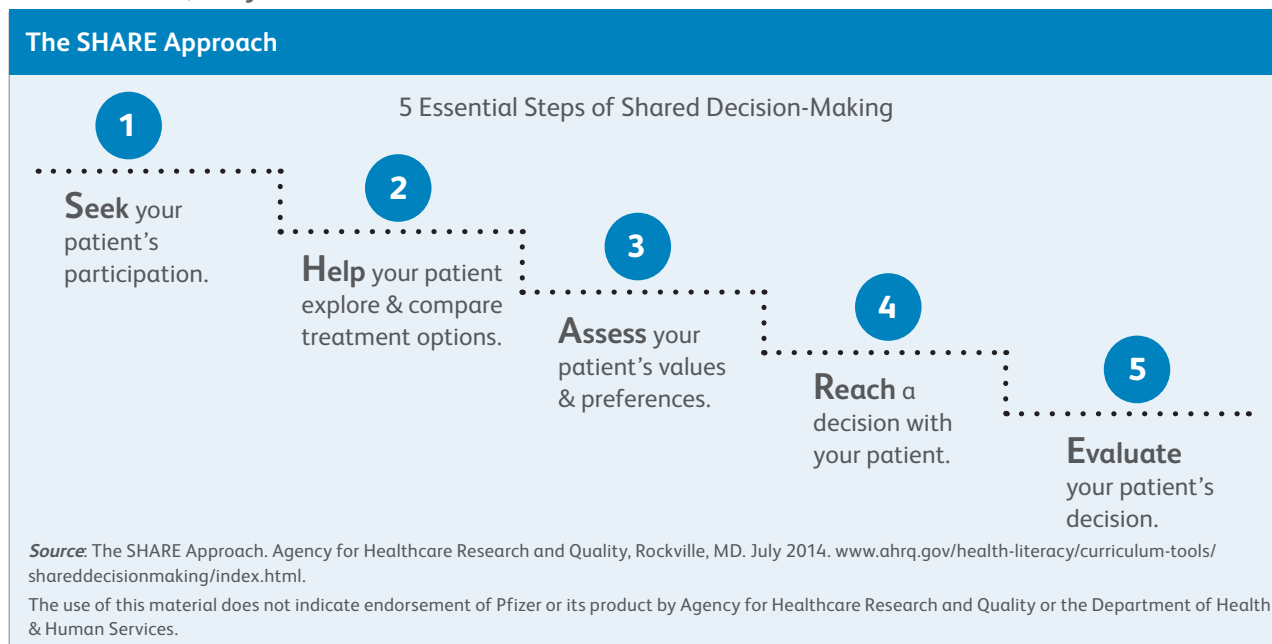
E: Evaluate your patient’s decision

SHARE Model for Clinical Decision-Making

An excellent model in SDM is the SHARE model, as illustrated in **Figure 1**.⁴ The SHARE approach is a 5-step process that includes exploring and comparing the benefits, harms, and risks of each option through meaningful dialogue about what matters most to the patient and family.⁴

Navigators can offer support to patients with advanced prostate cancer via the use of SDM resources, helping to instill confidence in patients and fostering their ability to exert some control over the circumstances. An SDM intervention might be as simple as having the patient write down the pros and

FIGURE 1. The SHARE Model for Shared Decision-Making Was Created by the Agency for Healthcare Research and Quality



cons of each decision. Ready-made tools are available online to help assist (*see Section XV in this toolkit*). One excellent example is the Ottawa Personal Decision Guide from the Ottawa Hospital Research Institute & University, which is illustrated in **Figure 2**.⁵ Its website also contains video tutorials on how the tools can be used. Ideally, navigators should use SDM tools during face-to-face encounters with patients and families, as opposed to completing them on their own at home. This will enable us to systematically and collaboratively step through the process. Patients newly diagnosed with advanced prostate cancer are met with complex decisions, with many of these people having no personal experience to guide them forward. Through the SDM process, navigators can impart knowledge and perspective via the shared experiences of past patients in similar clinical situations, coupled with the navigator's professional expertise.

Side Effects/Frequent and Open Communication Between Patients/Families and the Care Team

As the patient moves through the disease process, it is also important to focus on the management of symptoms. Open and frequent communication is crucial in assessing patients' symptoms. Many symptoms associated with the treatment of advanced prostate cancer deal with intimate, private issues related to sexual function, as well as bowel and bladder function. Other symptoms can be relatively vague and difficult to measure, such as hot flashes and nausea. It can be difficult for navigators and other healthcare providers to tackle the subject of sexual function with their patients. There are 2 models in the oncology care literature—PLISSIT and BETTER—that can assist in discussing these delicate matters.

PLISSIT Model: Addressing Sexual Function

One of the issues that needs to be discussed with the patient is whether he is sexually active or had been sexually active until the prostate cancer spread. PLISSIT is a 4-step model in a systematic approach to learning about a patient's sexual concerns and addressing any issues identified.⁶ The steps in the process are as follows⁶:

P = Permission: By being open, honest, and initiating a discussion about sex, the healthcare professional will grant the patient permission to express any concerns, needs, and feelings related to sexual function. Patients also are reassured that their feelings are shared by others in the same situation. Acknowledge that a patient with advanced prostate cancer may be focused on survival and not concerned about sexual function, whereas others may afford sexual function a higher priority.

LI = Limited Information: Patients are given limited information specific to their situation and sexual concerns, such as adverse physiologic changes from the effects of treatment or disease on sexual function, change in body image, and lack of libido.

SS = Specific Suggestions: Specific suggestions are provided to help patients manage or compensate for sexual dysfunction. In advanced prostate cancer, erectile function is the primary concern, but suggestions can also be made about alternative ways in which a person can provide pleasure to their partner.

IT = Intensive Therapy: Intensive therapy is the step where the sexual function intervention has reached the level at which the services of a trained specialist are indicated. It means that the first 3 levels of sexual counseling on the part of the healthcare professional have not resulted in resolution of the patient's problems and thus an outside referral is needed.

BETTER Model

Another model to aid in the discussion on sexual function, which is known as BETTER, was developed specifically for oncology nurses to address sexuality issues with their patients as part of a holistic, quality-of-life framework.⁶ Building upon PLISSIT, the BETTER model also includes suggestions on the

FIGURE 2. Ottawa Personal Decision Guide

Ottawa Personal Decision Guide

For People Making Health or Social Decisions

1 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 Close to choosing
 Thinking about it Made a choice

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

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

Support

Who else is involved?

Which option do they prefer?

Is this person pressuring you?
 Yes No Yes No Yes No

How can they support you?

What role do you prefer in making the choice?
 Share the decision with...
 Decide myself after hearing views of...
 Someone else decides...





Ottawa Personal Decision Guide © 2015 O'Connor, Stacey, Jacobsen. Ottawa Hospital Research Institute & University of Ottawa, Canada. Page 1 of 2



Source: Ottawa Hospital Research Institute. <https://decisionaid.ohri.ca/docs/das/OPDG.pdf>.

(continued)








FIGURE 2. Ottawa Personal Decision Guide (*continued*)

3 Identify your decision making needs. Adapted from The SURE Test © 2008 O'Connor & Légaré.

	Knowledge	Do you know the benefits and risks of each option?	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Values	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Support	Do you have enough support and advice to make a choice?	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Certainty	Do you feel sure about the best choice for you?	<input type="checkbox"/> Yes <input type="checkbox"/> No

If you answer 'no' to any question, you can work through steps two  and four , focusing on your needs. People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

4 Plan the next steps based on your needs.

Decision making needs	✓ Things you could try
 <p>Knowledge</p> <p>If you feel you do NOT have enough facts</p>	<input type="checkbox"/> Find out more about the options and the chances of the benefits and risks. <input type="checkbox"/> List your questions. <input type="checkbox"/> List where to find the answers (e.g. library, health professionals, counsellors): <div style="border: 1px solid #ccc; height: 40px; margin-top: 5px;"></div>
 <p>Values</p> <p>If you are NOT sure which benefits and risks matter most to you</p>	<input type="checkbox"/> Review the stars in step two  to see what matters most to you. <input type="checkbox"/> Find people who know what it is like to experience the benefits and risks. <input type="checkbox"/> Talk to others who have made the decision. <input type="checkbox"/> Read stories of what mattered most to others. <input type="checkbox"/> Discuss with others what matters most to you.
 <p>Support</p> <p>If you feel you do NOT have enough support</p> <p>If you feel PRESSURE from others to make a specific choice</p>	<input type="checkbox"/> Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends). <input type="checkbox"/> Find help to support your choice (e.g. funds, transport, child care). <input type="checkbox"/> Focus on the views of others who matter most. <input type="checkbox"/> Share your guide with others. <input type="checkbox"/> Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.) <input type="checkbox"/> Find a person to help you and others involved.
 <p>Certainty</p> <p>If you feel UNSURE about the best choice for you</p>	<input type="checkbox"/> Work through steps two  and four  , focusing on your needs.
<p>Other factors making the decision DIFFICULT</p> <div style="border: 1px solid #ccc; height: 50px; margin-top: 5px;"></div>	<p>List anything else you could try:</p> <div style="border: 1px solid #ccc; height: 50px; margin-top: 5px;"></div>

Ottawa Personal Decision Guide © 2015 O'Connor, Stacey, Jacobsen. Ottawa Hospital Research Institute & University of Ottawa, Canada. Page 2 of 2

Source: Ottawa Hospital Research Institute. <https://decisionaid.ohri.ca/docs/das/OPDG.pdf>.

timing of the discussion and on documentation. Any member of the oncology care team can follow this stepwise approach to addressing sexuality issues with their patients⁶:

B = Bring up the topic of sexual function with the patient. Nurses initiate this conversation and convey that it is an acceptable area for discussion. Baseline information regarding current sexual relationships or concerns is gathered as part of the sexual assessment. Clinical questionnaires, such as the National Comprehensive Cancer Network (NCCN) Distress Thermometer and Problem List tool or the Expanded Prostate Cancer Index Composite for Clinical Practice (EPIC-CP), can be used by nurses to introduce the subject. Then asking open-ended questions about quality of life related to sexual function can offer some additional insight.

E = Explain to the patient that sexual function is a quality-of-life issue and, therefore, an important area for the nurse to address. Sexual function is more than the physical act of intercourse and encompasses the mutual expression of love and affection shown by such intimate acts as hugging, kissing, and touching, and can have a positive effect on a patient's quality of life. Outside of sexual function, aspects of intimacy should be addressed, including physical (touch, hugs); intellectual (sharing ideas); emotional (sharing feelings); and shared activities (jobs, exercise, fun).

T = Tell the patient that many resources are available to provide information and guidance on issues related to sexual function and that the nurse or staff can assist in locating these resources.

T = Time the discussion on sexual function and intimacy to be appropriate to the patient's need to share and receive information. If the patient is not interested or is not ready to discuss or address these topics, the nurse responds that the patient will be able to receive information and assistance at any time if one so chooses.

E = Educate the patient about how side effects of cancer therapy can have a profound impact on one's interest and ability to perform sexually. As part of patient education about cancer treatments, nurses should ensure that patients receive and understand information regarding the possible sexual side effects of particular therapies.

R = Record the elements of the sexual function discussion between the patient and the nurse in the patient's healthcare record, including the sexual health assessment and interventions. This interaction should be documented to indicate that the topic has been discussed.

Providers need to educate patients about what to expect and how best to relay their concerns to the team. Navigators and other members of the care team can reach out to patients by phone or secure online messaging on a structured and periodic basis, depending on what phase of treatment is currently underway.

Nonclinical patient navigators can play an essential role here by asking the right

questions, collecting information from the patient and family members, and reporting that information to the appropriate clinicians on the healthcare team for follow-up. Disease-specific or treatment-specific flowsheets and questionnaires can be useful here. One example is the EPIC-CP form (www.bidmc.org/epic).⁷

The EPIC-CP proves to be an assessment tool that can be easily administered by navigators and other members of the oncology care team. At an initial visit, the navigator can include the EPIC-CP, along with such other baseline assessment tools as the NCCN Distress Thermometer and Problem List. Through collaboration with other departments, such as urology, medical, and radiation oncology, the EPIC-CP could be administered by other healthcare providers, with the subsequent sharing of data through the

Navigators and other members of the care team can reach out to patients by phone or secure online messaging on a structured and periodic basis, depending on what phase of treatment is currently underway.

electronic medical record helping all involved adapt promptly to the needs of the patient with advanced prostate cancer and family members.

Nurse navigators can go one step farther by synthesizing all the information collected, then assessing the situation for specific needs, whether physical, psychosocial, emotional, or practical. Rather than passively waiting for patients to report worrisome treatment-related symptoms or post-treatment latent side effects, navigators can turn this into a proactive process by reaching out to patients frequently and regularly during treatment. In this way, the care team can promptly address side effects as they develop or offer some reassurance to these patients by identifying the lack of side effects that could impact quality of life. With much of oncology care based in the outpatient setting, including patients self-administering oral therapies at home, communication is key to medication adherence, particularly given the variety of available agents for patients with advanced prostate cancer. The Oncology Nursing Society (ONS) has a robust patient education tool specifically related to oral chemotherapy adherence, which can greatly assist nurse and patient navigators in optimizing care in this arena. The WebLink to the full PDF version of the tool is included in the Resource Guide (*see Section XV of this toolkit*) and is listed in the references at the end of this section.⁸

Caregiver Issues

Whether it be a spouse, significant other, family member, or friend, many patients with advanced prostate cancer may have (and should have) a primary support person who is helping them in their cancer care journey. Men may be

less likely to reach out for help through their care continuum. By encouraging the active participation of the patient's support team with the healthcare team, navigators can extend purposeful support into the home setting. It is helpful to have many of the people involved in the patient's care present during conversations reviewing side effects, symptoms, and the overall treatment plan. These supporters also aid in gauging how the patient is coping both emotionally and physically. When patients present alone, navigating through the advanced prostate cancer experience can be more challenging.

Each meeting with the patient is a prime opportunity to gather information, in an effort to enhance quality of care. High-functioning, low-acuity patients may benefit from support groups or peer-support/buddy programs. For more complex cases, navigators may need to facilitate referrals to social workers, mental health professionals, or other clinical specialties. As an advocate for care for the patient with advanced prostate cancer and family members, it is critical for the navigator to understand the full plan of care established by the multidisciplinary team, so that the navigator can reinforce the plan, along with education about treatments and side-effect management. With an overarching view, the navigator can ensure that collaboration and communication among the healthcare team members are always in the best interests of the patient.

Compare/Contrast: Discussions with Physician versus Discussions with the Nurse Navigator

Conversations with the treating physician carry a much different weight and meaning for patients compared with conversations with the nurse navigator. The same questions addressed in both a physician visit and a navigator visit could potentially result in very different answers. Patients may be concerned about disappointing their physician and, therefore, will not report as many problematic symptoms or concerns. Patients are also more likely to report physical side effects to their physicians and to share fewer details on any psychosocial, emotional, or practical issues. In contrast, visits with the

With an overarching view, the navigator can ensure that collaboration and communication among the healthcare team members are always in the best interests of the patient.

nurse navigator may open the lines of communication on these nonclinical issues. Some patients and their families feel very comfortable with their nurse navigators and are more likely to confide in them and even to reveal symptoms or concerns that they do not disclose to their physicians. Given the inherent differences in communication with physicians versus navigators (or other members of the healthcare team), documentation and sharing of gathered information with the team can provide all of those involved with a better perspective on what is happening with the patient and family members. In-person meetings of the care team members may ultimately become regularly scheduled multidisciplinary clinics, tumor boards, or clinical rounds. Nurse navigators should take the opportunity to participate in these meetings and are often called upon to coordinate such meetings. The core group should include the treating physicians (surgical, medical, and/or radiation oncologists) and advanced practice providers; patient and nurse navigators; social workers; and such other support providers as genetic counselors, registered dietitians, palliative care providers, and financial navigators. During the intervals between the in-person meetings, multidisciplinary collaboration may need to take place as teleconference, or messaging and shared documentation in the electronic medical record. Given the recommendations of the team, the navigator can circle back to the patient and family to help adjust and advance the care plan.

After the provider has completed his or her discussion, it is important to ask the patient to state in their own words what the physician just said, so that the navigator can ensure that the patient accurately comprehended the information provided by the treating physician. Commonly, a physician may only ask the patient, “You understood what I said, right?” which requires only a yes or a no answer and does not ensure that the comprehension by the patient was correct. The navigator can engage this type of discussion first, then move on to other aspects of communication that address barriers to care, as well as other issues related to care and treatment, with which the navigator can assist.

Some patients and their families feel very comfortable with their nurse navigators and are more likely to confide in them and even to reveal symptoms or concerns that they do not disclose to their physicians.

Caregiver Strain

Amid the whirlwind of facing advanced prostate cancer, caregivers often put all their energy into supporting their loved one with the disease, yet caregiving itself can be very stressful. With cancer in the picture, the role of the caregiver must evolve and become adapted beyond the traditional expectations of support. The ONS denotes caregiver strain and burden as a symptom of cancer, formally defining it as follows:

“Caregiver strain and burden encompasses the difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver’s emotional and physical health that can occur when care demands exceed resources. Caregivers experience differing challenges during different phases of the cancer trajectory that can significantly impact their functioning and quality of life.”⁹

Paying attention to the needs of caregivers can be overlooked easily, given all the attention paid to patients with advanced prostate cancer, while minimizing the impact of caregiver strain on quality of life. Navigators should allow some time for caregiver check-in, as there are many resources available to encourage self-care of the caregiver (*see Section XV of this toolkit*). As a starting foundation, the National Cancer Institute has an excellent guide entitled *Caring for the Caregiver*, which is readily available online. This guide encourages caregivers to evaluate themselves, to ask for help, and to identify and utilize the resources available specifically for them, which are often underutilized.¹⁰

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IV. ADVANCED PROSTATE CANCER FACTS, MYTHS, AND MISCONCEPTIONS

MYTH/FACT #1: High PSA

MYTH: *“My PSA is still so high! I guess the treatments just aren’t working. I’m worried that pain and other symptoms are just around the corner.”*

FACT: *People with advanced prostate cancer can have a high PSA level, but still have good quality of life as a result of treatment, as well as understanding the context of the value.*

The prostate-specific antigen (PSA) blood test is already associated with controversy with respect to screening for prostate cancer, but with men already diagnosed and pursuing treatment for advanced prostate cancer, “normal” PSA levels take on a different meaning altogether. If prostatectomy has been performed, undetectable PSA would be the desired outcome, conventionally at ≤ 0.1 ng/mL. Therefore, recurrence is a concern if PSA levels become detectable, and follow-up treatment may be warranted for PSA levels as low as 0.2 ng/mL, when considered in conjunction with additional laboratory and imaging studies.¹ Baseline PSA levels following radiotherapy will be higher than baseline PSA levels after surgery, because normal prostate cells remain after radiotherapy, and these cells still produce PSA. As a result, PSA levels drop slowly after radiation and may not reach their lowest value until 2 years or more post-treatment.²

A rising PSA level on consecutive tests following treatment, or a 2-ng/mL rise from the lowest level ever reached, may be an indication that cancer remains.² In patients with metastatic disease, PSA levels can be very high, even in the hundreds to thousands. Symptoms may not have appeared or are not extreme enough to significantly affect quality of life, because of ongoing treatments and supportive care. It is expected that PSA levels will decrease or stabilize while

patients are on hormone therapy and chemotherapy. However, with the radioisotope radium-223 dichloride, the PSA level does not correspond with the response to therapy, and levels may even rise over the course of treatment.³ Rather than looking solely at high PSA levels, the PSA doubling time (PSADT) may be a more important indicator of progression on which to focus, when considered along with other laboratory values and imaging results. Research has shown a strong association between PSADT and increased risk for metastases.⁴ Therefore, PSADT can help navigators remain aware of potential adjustments in the goals of care for patients with advanced prostate cancer.

Separate from the value of the PSA and PSADT, the number and location (bone vs visceral) of metastatic sites can provide some insight into relative success of treatments for advanced prostate cancer. Findings from one study comparatively show that median overall survival/cancer-specific survival were most favorable for lymph node metastases (43 months/61 months), followed by bone (24 months/32 months), then visceral (16 months/26 months), and visceral plus bone (14 months/19 months).⁵

High PSA alone may not be a good indicator of treatment success in advanced prostate cancer, but other indicators such as PSADT and the specific characteristics of metastases can illustrate a clearer picture of how the patient is responding to treatment while also considering an assessment of quality of life.

Research has shown a strong association between PSADT and increased risk for metastases. Therefore, PSADT can help navigators remain aware of potential adjustments in the goals of care for patients with advanced prostate cancer.

MYTH/FACT #2: Familial and Genetic Risk

MYTH: “As a prostate cancer patient, it doesn’t affect my brothers, sons, or daughters with respect to cancer risk. I probably can’t get genetic testing, because it’s probably not covered by insurance.”

FACT: Recent updates in clinical guidelines have increased the availability of genetic testing for people with advanced prostate cancer, either with or without a family history of cancer (depending on exact clinical stage). Insurance coverage for testing is often available, once formal cancer genetic counseling is completed.

Hereditary cancer risk is often on the clinical radar for patients with breast and ovarian cancers. Genetic counseling and testing for the *BRCA1* and *BRCA2* mutations have become part of the standard workup for these patients, but recently the criteria have been expanded to include prostate cancers, given the risk associated with these genes, among others. Most patients who qualify for *BRCA1* and *BRCA2* genetic testing have the option for multigene germline genetic testing, allowing for the evaluation of a spectrum of genes related to risks for multiple cancer types. Once a hereditary risk has been identified through genetic testing, cascade family testing can further reveal cancer risks in those without cancer who may benefit by being screened more aggressively or by receiving risk-reduction interventions.⁶

Nurse navigators, treating physicians, and other healthcare team members should be aware of these newer criteria, so that they may recognize when patients with advanced prostate cancer should be referred to a genetics professional.

With respect to advanced prostate cancer, guidelines from the National Comprehensive Cancer Network (NCCN) support consideration of *BRCA1*- and *BRCA2*-related genetic counseling and testing based on the following criteria⁷:

- Personal history of metastatic prostate cancer, regardless of family history
- Personal history of high-grade prostate cancer (Gleason score ≥ 7) at any age with:
 - ≥ 1 close blood relatives with ovarian, pancreatic, or metastatic prostate cancer at any age or breast cancer < 50 years; or
 - ≥ 2 close blood relatives with breast or prostate cancer (any grade) at any age; or
 - Ashkenazi Jewish ancestry.

Nurse navigators, treating physicians, and other healthcare team members should be aware of these newer criteria, so that they may recognize when patients with advanced prostate cancer should be referred to a genetics professional (genetic counselors, advanced practice genetic nurse, or geneticist/physician specialist), as this benefits the patient and family members with cancer risk reduction.

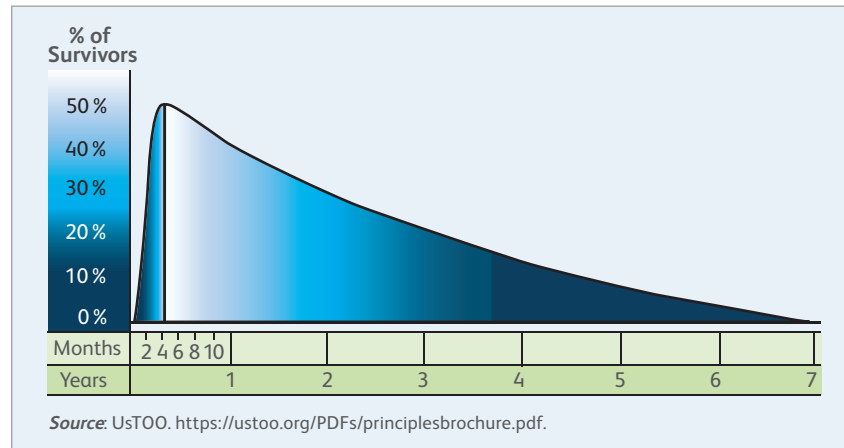
MYTH/FACT #3: Prognosis in Advanced Prostate Cancer/ Misinterpreting the Data

MYTH: “I was reading up on the chemotherapy that I will be getting. Doesn’t look promising; they keep referring to ‘median overall survival’ of 4 months or 8 months. Does that mean most patients only live 4 to 8 months in total?”

FACT: When reading statistics about median overall survival, they are not referring to the average length of survival, but rather, the time from the start of a treatment until the point where 50% of that group of patients are alive. Depending on the study, the remaining 50% may live longer than 4 to 8 months. However, some could live less than 4 to 8 months.

In cases of advanced prostate cancer, as patients meet with their treating physicians to discuss the complex treatment regimens and variety of medications they will be taking, there may be a lot of reference to clinical studies and their statistics. Even for the most well-educated patients, many of these statistics can be confusing and easily misinterpreted. For example, if the median overall survival of patients with advanced prostate cancer treated with a certain drug is 4 months, the chance of living longer than 4 months is 50%, with some patients living longer and some living shorter, as shown in **Figure 1**.⁸ An accurate understanding of how data are presented in cancer treatment can greatly reduce stress in patients with advanced prostate cancer, especially when learning about the treatments they are about to undertake.

FIGURE 1. Graph Representing Median Overall Survival Rate



For example, if the median overall survival of patients with advanced prostate cancer treated with a certain drug is 4 months, the chance of living longer than 4 months is 50%, with some patients living longer and some living shorter, as shown in **Figure 1**.⁸ An accurate understanding of how data are presented in cancer treatment can greatly reduce stress in patients with advanced prostate cancer, especially when learning about the treatments they are about to undertake.

MYTH/FACT #4: Post-Prostatectomy

MYTH: *“I had surgery for prostate cancer the first time, so the surgeon must have done something wrong. Getting cancer after surgery should be impossible!”*

FACT: *Even with prostatectomy performed properly, cancer cells can still travel into the surrounding tissue or nodes or enter the bloodstream and travel to the bone or elsewhere in the body, where they can be totally undetectable.*

People who present with advanced prostate cancer after having had a prostatectomy may express this frustration, especially if their surgery was deemed optimal and with no concerning factors such as positive margins, a Gleason score <7, or lymph node invasion on pathology review. When PSA levels become detectable (biochemical recurrence), this may lead to imaging and other tests that reveal progression of the cancer, even if the patient remains asymptomatic. The immediate post-surgical stage and grade of cancer found may help assess the risk for recurrence, yet the plan for monitoring regardless of risk level is often standard, with PSA checks at least every 6 to 12 months for the first 5 years, then yearly thereafter and a yearly digital rectal examination, which may be omitted if the PSA level is undetectable.

Cancer, by nature, is a challenging disease, so even with the most definitive of treatments within the most favorable situation, recurrence of disease is always a concern. For people with advanced prostate cancer and their families, looking backward to search for blame may be an initial reaction, but it is more productive to focus on what we can try to control or how we can affect change, looking forward.

MYTH/FACT #5: Elderly Patient with Advanced Prostate Cancer

MYTH: *Physician—“At the patient’s age, it’s just too late for treatment.”*

FACT: *After a comprehensive geriatric assessment, some elderly patients may reveal themselves to be prime candidates for relatively aggressive therapy, provided the benefits outweigh the risks and depending on any current diseases and disorders they are being treated for and how their overall health and well-being measures out to be.*

In agreement with the NCCN Guidelines on Older Adult Oncology, age alone should never be the sole determinant of treatment risk during the decision-making process.⁹ Simple validated geriatric screening tools are available to help clinicians assess the older adult's ability to tolerate anticancer therapy. Beyond the standard life expectancy table, there are online interactive calculators to assess geriatric status using a series of questionnaires; an excellent example is ePrognosis from the University of California San Francisco, accessible at <https://eprognosis.ucsf.edu/calculators/#/>.¹⁰ A comprehensive geriatric assessment will evaluate a spectrum of factors, including⁹:

- Functional status
- Comorbidities that may interfere with cancer treatment
- Polypharmacy
- Nutritional status
- Cognitive function
- Psychological status
- Socioeconomic status
- Geriatric syndromes.

Emerging technologies in the treatment of advanced prostate cancer, notably in chemotherapy, immunotherapy, radiotherapy, and androgen receptor pathway medications, offer many amenable treatment options with manageable side-effect profiles, even for the elderly oncology patient. Proper evaluation for treatment and support in treatment decision-making may sometimes require second opinions with other potential treating physicians; patients are justly in a position of control when they are “interviewing” physician prospects, in an effort to “hire” the right person for the job.

MYTH/FACT #6: Financial Concerns

MYTH: *“Treatment is too expensive, and probably won’t be covered.”*

FACT: *Even with the complex regimens offered to people with advanced prostate cancer, there may be financial assistance programs and other strategies available to help the underinsured or uninsured.*

Financial toxicity is a major concern when facing the diagnosis of advanced prostate cancer. Even those with insurance coverage may still have a substantial out-of-pocket cost. Often underutilized, financial navigation services can offer substantial help, identifying assistance programs that fit

Financial toxicity is a major concern when facing the diagnosis of advanced prostate cancer.

the patient's clinical picture so that out-of-pocket cost can be minimized. (See Section V of this toolkit for more information on Financial Navigators.) Nurse and patient navigators may also provide further support in reducing financial toxicity, while ensuring broad access to care specific to the patient's stage and grade of advanced prostate cancer. For example, navigators can collaborate with the oncology social worker to assist in finding financial assistance programs that help with meeting copayments, arranging low-cost transportation, or other practical issues.

MYTH/FACT #7: Advanced Prostate Cancer, but Symptom-Free

MYTH: *“I can’t believe my PSA is rising, and the CT scan was positive for a lymph node! I don’t have any symptoms, so how can I still have advanced prostate cancer?”*

FACT: *Despite findings of advanced cancer, patients may not have experienced any symptoms prior to this discovery.*

With so many technological advances in the diagnosis, staging, and treatment of advanced prostate cancer, we can sometimes find advanced disease well before any symptoms are noticed by the patient. Through close monitoring following primary treatment, lab values and imaging results can reveal advanced prostate cancer, and sometimes, the initial presentation of prostate cancer may include nodal or metastatic disease without a history of known localized disease. A rising PSA/

biochemical recurrence may necessitate advanced imaging scans such as a positron emission tomography/computed tomography or positron emission tomography/magnetic resonance imaging, which are more likely to identify asymptomatic advanced disease, as opposed to conventional bone scans. People with asymptomatic metastatic castration-resistant prostate cancer may qualify for treatments, such as sipuleucel-T, which is not routinely available to those who express higher levels of symptoms. Given this phenomenon, navigators can proactively stress the importance of adhering to the plan for clinical follow-up even in the absence of symptoms, after either primary treatment for clinically localized disease or ongoing treatments for advanced prostate cancer, as careful monitoring may potentially reveal advanced disease well before it is noticed by the patient.

Navigators can proactively stress the importance of adhering to the plan for clinical follow-up even in the absence of symptoms, after either primary treatment for clinically localized disease or ongoing treatments for advanced prostate cancer, as careful monitoring may potentially reveal advanced disease well before it is noticed by the patient.

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V. NAVIGATION IN THE CONTEXT OF ADVANCED PROSTATE CANCER

The Academy of Oncology Nurse & Patient Navigators (AONN+) defines the process of navigation as, “Helping patients overcome healthcare system barriers and providing them with timely access to quality medical and psychosocial care from before cancer diagnosis through all phases of their cancer experience.”¹ Typically, there is not just one navigator working on behalf of the patient, but rather a variety of people collectively working to move the process along. Although their job titles may or may not contain the word “navigator,” they remain a crucial part of the navigation process. Role delineation is key, especially considering the present common classifications of clinically licensed navigators (registered nurse/oncology nurse navigators and social work navigators), patient navigators (financial and lay navigators), and the community health worker (CHW). (See *General Navigation Toolkit, Section V, p. 13, and Section VI, p. 15.*)

Professionals in navigation hold a vast array of licensure and certifications. Clinically licensed navigators are often oncology nurses or social workers, yet other licensed specialties can be essential to navigation, including registered dietitians and clinical trial nurses, among others. Navigators without a clinical license can carry valuable certifications in support of their role, including the CHW certification or certifications earned from patient navigator training programs. Although there may be some overlap in these roles and services, they still offer distinct benefits for patients, families, and the overall process of navigation. (See *General Navigation Toolkit, Section IV, “Navigation Core Competencies,” as well as Section V, “Navigator Role Delineation,” and Section VI, “Models of Navigation,” for more information about roles and models of navigation.*)

Examples of roles and support services are described in this section within the context of the patient with advanced prostate cancer. This is by no means a comprehensive list, and additional roles may be determined as needed to fill gaps, once a proper community needs assessment is completed for your specific cancer program. (See *General Navigation Toolkit, Section II, for more information about community needs assessments.*)

Nurse Navigators in Advanced Prostate Cancer

The role of the nurse navigator is well-defined, as discussed in the *General Navigation Toolkit*. However, navigation of advanced prostate cancer carries its own distinct characteristics that require addressing specific issues related to program and staff development. In working with patients who have advanced prostate cancer, nurse navigators can enter their role with substantial experience already in place for a specialty such as urology, radiation oncology, or medical oncology. Conversely, an oncology nurse navigator who is new to the field of advanced prostate cancer can pursue specific educational programs, through organizations such as the Oncology Nursing Society and AONN+, to build a foundation of knowledge for practice. As clinically licensed navigators, they can educate, assess, and intervene, to keenly address the physical and psychosocial needs of the patients and their families and caregivers. The measures of success for the role of the nurse navigator should be clinical outcomes and quality indicators.

Navigation of advanced prostate cancer carries its own distinct characteristics that require addressing specific issues related to program and staff development.

Models of navigation vary greatly across different cancer programs and practices. Some navigators address the entire cancer care continuum, from diagnosis through treatment and into follow-up. Other navigators may focus primarily on a section of the continuum; for example, from an initial finding of advanced prostate cancer to handing off to the treating physicians, care team, and perhaps other navigators. Regardless of the phase of care, the nurse navigator is often the primary contact and advocate for the patient and family, facilitating communication with the oncology care team. Consultations with the treating physician and any specialty services can provide patients and families a copious amount of information, so following up with the nurse navigator regularly allows for assessment of any learning needs that require clarification or reinforcement. Nurse navigators can also address any psychosocial or practical needs that are discovered during their assessment or refer these needs to the social work navigator and other members of the care team. Optimally, cancer centers utilize both nurse and social work navigators so that responsibilities can be distributed and delegated, with nurses taking on more of the clinical aspects and social workers helping with psychosocial and insurance issues.

Nurse navigators can also address any psychosocial or practical needs that are discovered during their assessment or refer these needs to the social work navigator and other members of the care team.

Social Work Navigators

To enter their profession, social workers must have completed a master's-level degree of education. For those working in oncology, they may pursue the Oncology Social Work Certification. Similar to nurse navigators, social work navigators also are clinically licensed, but their expertise is more heavily weighted in the psychosocial, emotional, and spiritual aspects of the care continuum, as opposed to the physical aspects. Oncology social workers can pursue continuing education through their own professional organizations, including the Association of Oncology Social Work or through partner organizations such as AONN+.

Given the complexity of care required in advanced prostate cancer, the nurse and patient navigator may already be working hard to address clinical and logistic needs, so the social work navigator is key in helping with the emotional and practical issues of the disease. Social work aids in coping with practical concerns by providing yet another educational/supportive resource to help patients understand their treatment plan, as well as another patient advocate to work with the healthcare team. Finding financial assistance for patients is often best addressed by the social work navigator.

Patient Navigators

Patient navigators who are not clinically licensed are tasked with increasing access to care and removing potential barriers by guiding the patient through the healthcare system. They help patients communicate with their healthcare providers so they can get the information needed to make decisions about their own care. To make the care process smooth and efficient, patient navigators can arrange appointments for physician visits and medical tests, as well as provide further support regarding finance, legal, social, and practical issues. Patient navigators can also help identify barriers to care and health disparities within the community and provide resources for eliminating those barriers. Continuing education can be obtained through AONN+ as well, or other professional organizations, including the American Cancer Society and The Alliance of Professional Health Advocates.

Professionals who carry the CHW certification can provide patient navigation services as part of their role. The Centers for Disease Control and Prevention outlines the main differences between CHWs and patient navigators, as follows²:

- Patient navigators are assigned to specific patients; CHWs often are not
- The duties of patient navigators are a subset of CHW duties
- Patient navigators may have other occupational backgrounds
- Patient navigation is a role or function; community health work is a distinct occupation.

CHWs may have less individual patient interaction but have a greater impact through their work at the community level, looking at aggregative needs and trends in behavior that may affect quality of care.

For patients with advanced prostate cancer, navigation services as administered by professionals without clinical licenses (including dedicated patient navigators in collaboration with CHWs, where available) offer a perfect complement to the navigation provided by clinically licensed professionals. Given the complexities of care for these patients, disease-specific training and education enable patient navigators to further contribute to professional development in this field.

Financial Navigators

Financial navigators assist patients and their families by helping to reduce stress or hardship related to the cost of cancer care. They aim to help patients understand their out-of-pocket expenses and instruct them on what their health insurance plans may cover. Other interventions include setting up payment plans, finding cost-saving methods for treatment, and improving overall access to healthcare services needed. Continuing education for these professionals can be obtained through AONN+, or other professional organizations, including the Association of Community Cancer Centers.³

Patients with advanced prostate cancer often have intricate care plans that carry a high risk for financial burden, which may be inadequately addressed by nurse, social work, or patient navigators. Professionals skilled in financial navigation can have great impact on quality of life, by reducing or preventing any distress caused by the cumulative cost of cancer treatment incurred over the care continuum.

Registered Dietitian: Navigating Diet and Nutrition

A registered dietitian is a master's-level-prepared health professional who has special training in diet and nutrition. Dietitians advise on nutrition and healthy eating to help prevent and treat conditions, such as food allergies and conditions caused by diabetes, heart disease, and cancer. Dietitians may provide nutritional counseling, meal planning, medical nutrition therapy (eg, special diets, dietary supplements, and intravenous/tube feedings), or nutrition education programs.

Dietitians who specialize in oncology can tackle certain complicated issues as they arise, particularly in people with advanced prostate cancer. Prostate cancer treatment has the potential to negatively affect appetite, eating habits, and weight—but for these patients, it is crucial to maintain a healthy weight and take in essential nutrients, while remaining as physically active as possible. During intensive treatments or multimodal therapy, periodic assessments by the registered dietitian can help the patient, caregivers, and healthcare team adapt to nutritional needs as they fluctuate during this time. Navigating diet and nutrition along with an oncology registered dietitian can allow patients to take an active role in optimizing their cancer care.⁴

Navigating diet and nutrition along with an oncology registered dietitian can allow patients to take an active role in optimizing their cancer care.

Cancer Rehabilitation: Navigating Preparation for Treatments and Recovery

Although often associated with cancer survivorship, cancer rehabilitation services can also be helpful to patients with advanced prostate cancer, since treatments can cause physical, psychological, and cognitive problems. The registered dietitian is included under the umbrella of cancer rehabilitation, but there are numerous specialties available, including⁵:

- **Physical therapist (PT).** PTs specialize in helping people improve or restore mobility. They can also help reduce or eliminate pain. Oncology PTs work specifically with people who have cancer and cancer survivors. Pelvic physical therapy can be helpful for patients with treatment-related incontinence
- **Physiatrist.** Physiatrists are also called physical medicine and rehabilitation specialists. They specialize in the prevention, diagnosis, and treatment of nerve, muscle, and bone disorders that can change how people move and function. These specialists often work with people on pain management
- **Cognitive psychologist.** Cognitive psychologists, also called neuropsychologists, are experts in understanding how behavior relates to brain function. They often help manage “chemo brain,” a word used to describe the cognitive problems that people with cancer often face during and after cancer treatment
- **Exercise physiologist.** Exercise physiologists analyze a person’s fitness to help them improve function. Using stress tests and other tools, they evaluate cardiovascular function and metabolism. They can also design fitness plans that meet the needs of people during and after cancer treatment.

The cancer rehabilitation team is effectively fighting barriers to recovery in alignment with cancer navigation.

The cancer rehabilitation team is effectively fighting barriers to recovery in alignment with cancer navigation. Proactively, the navigator for patients with advanced prostate cancer may even want to consider referral to cancer rehabilitation prior to treatments, so patients can be assessed for their

baseline strength and mobility. This aids in more effective monitoring throughout treatment and beyond, and helps address any issues that arise early, before they become more serious. For example, PTs, cognitive psychologists, and dietitians can be excellent resources for patients receiving hormonal treatments or chemotherapy, given the risk for fatigue, muscle weakness, and “chemo brain” cognitive issues. Physiatrists can be a great addition to the pain management team in patients with advanced prostate cancer who are symptomatic.

Genetic Counselors: Navigating Genetics/Genomics

In just the past few years, access to genetic and genomic technologies in the field of advanced prostate cancer has greatly increased. Genetic counseling is now essential to all patients with the disease; therefore, navigators should ensure that referrals are made promptly in consideration of germline testing, as well as somatic tissue testing. The care trajectory of the patient can be impacted by genetics and genomics, but also, the family’s cancer risk may be better assessed after a thorough genetic evaluation, including intervention in proactive screening and preventive measures, if an inherited gene mutation is found. *(See Section X of this toolkit regarding updated genetic testing criteria, as well as the role of navigators and genetic counselors in this space.)*

Peer Programs/Buddy Programs

Peer support offers a valuable component of care not directly addressed by the healthcare team, given the unique aspect of firsthand patient experience. The knowledge barrier of “not knowing what to expect” is a

weighty concern for people facing the initial diagnosis of advanced prostate cancer, so learning from those who have been through it, or are going through it now, can greatly reduce or prevent distress through the shared experience. Navigators, physician offices, or even community groups may compile and maintain lists of patients who are willing to connect with other patients for peer support, sometimes labeled as “buddy programs.” To serve in this capacity, these individuals should go through a formal training program and be covered for liability by the healthcare professional group or institution they are representing. With this type of support, it needs to be made clear to recipients that no medical advice is being given, but rather that these patients are solely sharing their own experiences of diagnosis, treatment, and aftercare. A professional member of the navigation team can help orient new buddies to what is expected of them, as well as their boundaries in providing peer support; ongoing feedback from buddies and the patients they interact with should be collected to ensure the quality of peer support given.

Peer support may be in-person, with individual visits or phone calls. Live support groups, moderated by social work, provide a group arena for peer support. Online support groups and discussion boards can also be useful, if properly supervised and moderated by an appropriate professional; the resource Us TOO has an online search tool for support groups specific to prostate cancer (www.ustoo.org/Support-Group-Near-You). Other advocacy organizations found online offer peer-support programs that connect patients with similar prostate cancer histories for individualized social support, including ZERO MENtor program (www.zerocancer.org/get-support/mentor) and other regional programs such as the Prostate Cancer Foundation (www.pcf.org/patient-resources/patient-navigation/support-groups) or the National Cancer Institute (<https://supportorgs.cancer.gov/home.aspx?lang=1> [click on “Choose from a list of services,” then select “Peer/Buddy Programs”]).

Clinical Trials Team

Treatment advances over the past 2 decades have extended the lives of those with advanced prostate cancer and would not have occurred without innovation through clinical trials. Patients with advanced prostate cancer who are eligible for clinical trials may wind up not being evaluated for or enrolled in these studies, mostly because of a potential lack of awareness by both patients and physicians, creating a barrier that remains undiscovered for those involved. Clinical trial nurses and coordinators who often make up the bulk of the clinical trials team can best help navigate patients past these barriers, and at the very least, give them the option to enter clinical trials that fit their situation. Other barriers that may keep patients from joining a clinical trial include housing, phone/Internet access, health insurance, citizenship/legal residence status, treatment for comorbidity, low English language skills or literacy levels, or fear/mistrust of clinical research. Barriers that keep patients from staying in a clinical trial include practical barriers (ie, transportation, childcare, work schedules), lack of understanding of the healthcare system, language or literacy, and cultural differences.⁶

Beyond just the elements of education or referral, the navigator’s role regarding clinical trials is to help patients understand them, generate interest, and reduce barriers to enrollment or continued participation in trials. Ultimately, physicians are responsible for deciding patient eligibility to join a trial. Understanding the basics of clinical trials and how they pertain to patient care is within the navigator’s scope of practice, in support of navigation to clinical trials. (*See Section XV of this toolkit for more information.*)

References: 1. Academy of Oncology Nurse & Patient Navigators (AONN+). 2019. Helpful definitions. www.aonnonline.org/education/helpful-definitions. Accessed July 23, 2019. 2. Centers for Disease Control and Prevention (CDC). CHWs vs. patient navigators. www.cdc.gov/dhdsp/chw_elearning/s1_p9.html. Accessed July 23, 2019. 3. Association of Community Cancer Centers. Financial advocacy guidelines. www.acc-cancer.org/home/learn/financial-advocacy/guidelines. 2018. Accessed July 23, 2019. 4. Baguley BJ, Bolam KA, Wright ORL, Skinner TL. The effect of nutrition therapy and exercise on cancer-related fatigue and quality of life in men with prostate cancer: a systematic review. *Nutrients*. 2017;9:1003. doi: 10.1002/nur.21977. Epub 2019 Aug 7. 5. American Society of Clinical Oncology. Cancer.net. What Is Cancer Rehabilitation? www.cancer.net/survivorship/rehabilitation/what-cancer-rehabilitation. Accessed July 23, 2019. 6. Patient Navigator Training Collaborative. Clinical Trials and Patient Navigation. Addressing Barriers to Clinical Trials. www.patientnavigatortraining.org/clinical_trials/module_3/index.htm. Accessed July 23, 2019.



VI. NAVIGATION CORE COMPETENCIES SPECIFIC TO ADVANCED PROSTATE CANCER

Care coordination has always been a major focus of the oncology nurse's role. In 2011, the Oncology Nursing Society (ONS) recognized that an increasing number of oncology nurses identified nurse navigation as their primary function.¹ ONS then developed the Oncology Nurse Navigator Competencies in 2013, with a 2017 update to reflect the evolution of the role.¹ Several years ago, the Academy of Oncology Nurse & Patient Navigators (AONN+) established a navigation certification program using the evidence-based domains (**Table 1**), which cover all areas in which navigators practice to provide quality patient care and financial stability for their organizations.²

In the pursuit of the optimal navigation process, nurse and patient navigators should demonstrate core competency in each of the 7 domains listed below, as outlined by the National Navigation Roundtable³⁻⁵ (see also *General Navigation Toolkit, Section IV, p. 11-12*).

Specific tasks can assist navigators in reaching and maintaining these core competencies, which are essential to their professional practice in serving patients and families facing advanced prostate cancer. Examples of these tasks are listed below each domain. This is by no means a comprehensive list, but hopefully will prompt discussions among the team providing and supporting the navigation process at your center.

TABLE 1. AONN+ Knowledge Domains

Community Outreach and Prevention
Coordination of Care/Care Transitions
Patient Advocacy/Patient Empowerment
Psychosocial Support Services/Assessment
Survivorship/End of Life
Professional Roles and Responsibilities
Operations Management/Organizational Development/Healthcare Economics
Research/Quality/Performance Improvement

AONN+ indicates Academy of Oncology Nurse & Patient Navigators.

Source: Strusowski T, Johnston D. *J Oncol Navig Surviv*. 2018;9:214-221.

I. Domain: Ethical, Cultural, Legal, and Professional Issues

Competency: Demonstrates sensitivity and responsiveness to a diverse patient population, including, but not limited to, respecting confidentiality; organizational rules and regulations; ethical principles; and diversity in sex, age, culture, race, ethnicity, religion, abilities, sexual orientation, and geography.

Tasks:

- Evaluate healthcare facility's policies in place that address patient confidentiality; may need to collaborate with administration and/or compliance officer
- Identify the groups that are most commonly served by the facility, particularly characteristics of diversity as outlined above; may be completed as a part of a community needs assessment (see *General Navigation Toolkit, Section VI*)
- Identify educational resources aimed at optimizing culturally competent care; may include live or online continuing education activities and teaming up with community organizations that also serve cultural groups
- Identify prostate cancer-specific educational and support resources to have readily available (see *this toolkit, Section XV*).

II. Domain: Patient/Client and Care Team Interaction

Competency: Applies insight and understanding concerning human emotional responses to create and maintain positive interpersonal interactions leading to trust and collaboration among patient/family/caregivers and the healthcare team. Patient safety and satisfaction are priorities.

Tasks:

- Collaborate with social workers and other mental health providers on the care team, to determine local best practices
- Identify systems in place that are aimed at assessing mental health/distress in patients and families (*see information on the National Comprehensive Cancer Network [NCCN] Distress Thermometer in this toolkit, Section VIII, and in the General Navigation Toolkit, Section VIII, p. 23-27*)
- Identify professional development activities centered on communication skills in patient care and among members of the healthcare team
- Develop and maintain multidisciplinary tumor boards
- Consider prostate cancer multidisciplinary care team visits.

III. Domain: Health Knowledge

Competency: Demonstrates breadth of knowledge about health, the cancer continuum, psychosocial and spiritual aspects, and attitudes and behaviors specific to their patient navigation (clinical/licensed or nonmedical licensure) role.

Tasks:

- Complete educational activities geared toward the navigator's basic understanding of cancer care in advanced prostate cancer, including cancer screening, diagnosis, treatment, and follow-up care
- Interview physician and nurse providers on the advanced prostate cancer healthcare team to determine current standard practices and identify gaps that may be best addressed by navigation
- Collaborate with social workers, registered dietitians, genetic counselors, and other allied health staff to best understand team responsibilities related to physical, emotional, social, and practical issues in cancer care.

IV. Domain: Patient Care Coordination

Competency: Participates in the development of an evidence-based or promising/best practice patient-centered plan of care, which is inclusive of the patient's personal assessment as well as healthcare provider system and community resources. The navigator acts as a liaison among all team members to advocate for patients to optimize health and wellness with the overall focus of improving access to services for all patients. Navigators conduct patient assessments (needs, goals, self-management, behaviors, strategies for improvement) integrating patients' personal and cultural values.

Tasks:

- Evaluate the current state of care provided at your facility for advanced prostate cancer, ensuring that it is in alignment with guidelines from the National Comprehensive Cancer Network
- Identify key team members with whom navigators need to work closely, and on a continuing basis, to facilitate care of the patient with advanced prostate cancer as well as family members; determine any service agreements or best practices common to the care continuum in advanced prostate cancer
- Take the lead in coordinating clinical care through tumor boards, patient education, care coordination across the continuum and across systems, etc (applies to clinically licensed navigators)
- Take the lead in logistics, which can include the scheduling of appointments, identification and referral to resources, etc (applies to nonclinically licensed navigators)

- Check in frequently with patients, caregivers, and family members to evaluate physical, emotional, social, and practical status, as it may fluctuate greatly from diagnosis through treatment.

V. Domain: Practice-Based Learning

Competency: Optimizes navigator practice through continual professional development and the assimilation of scientific evidence to continuously improve patient care, based on individual navigator gaps in knowledge, skills, attitudes, and abilities. (See *General Navigation Toolkit, Section XVI, "Navigation Topics for Professional Development," p. 59-61.*)

Tasks:

- Attend conferences and continuing education specific to the role of navigation in cancer care, including the ONS Annual Congress, the AONN+ Midyear and Annual conferences, the Association of Oncology Social Work national conferences, The George Washington University Cancer Center's Patient Navigation Educational programs, and ONS and AONN+ online educational offerings. (See *this toolkit, Section XV, and the General Navigation Toolkit, Section XVIII, "Navigation Resources."*)
- Develop relationships with colleagues within and outside of the healthcare facility to maintain a broad, varied perspective of optimal care as it applies to advanced prostate cancer, particularly through collegial organizations such as AONN+; advance professional practice through the shared experience, along with community-based networking opportunities through AONN+ local navigator networks
- Mentor new navigators to further contribute to quality care as a whole (see *General Navigation Toolkit, Section XII, "Navigation Program Development," p. 45-46*)
- Consider conducting research studies or projects in quality assurance and quality control that are specific to the navigation process, with a variety of opportunities to submit to AONN+ national conferences for abstract/poster presentations, or publish manuscripts in peer-reviewed journals, including the *Journal of Oncology Navigation & Survivorship, Clinical Journal of Oncology Nursing, Oncology Forum, and CANCER.*

VI. Domain: Systems-Based Practice

Competency: Advocates for quality patient care by acknowledging and monitoring needed (desirable) improvements in systems of care for patients, from enhancing community relationships and outreach through end-of-life care. This includes enhancing community relationships and developing skills and knowledge to monitor and evaluate patient care and the effectiveness of the program.

Tasks:

- Evaluate care system in place and identify any gaps or limitations that can be addressed by navigation; may be completed as part of a community needs assessment (see *General Navigation Toolkit, Section VI, "Models of Navigation"*)
- Measure, collect, and report on navigation metrics (see *General Navigation Toolkit, Section XIII, "Navigation Program Monitoring and Outcome Measures"; also see Journal of Oncology Navigation & Survivorship metrics article – May 2017, Vol. 8, No. 5, Standardized Evidence-Based Oncology Navigation Metrics for All Models. Available online at www.jons-online.com/issues/2017/may-2017-vol-9-no-5/1623-value-impact-of-navigation-programs*)
- Identify key relationships with community-support providers (eg, disease-specific nonprofits, advocacy groups, palliative and hospice care, peer support groups, etc) (see *this toolkit, Section XV*)
- Interview patients, caregivers, and families for firsthand feedback on their experience of the healthcare system as a whole, and gather suggestions on opportunities and challenges for change.

VII. Domain: Communication/Interpersonal Skills

Competency: Promotes effective communication and interactions with patients in shared decision-making based on their needs, goals, strengths, barriers, solutions, and resources. Resolution of conflict among patients, family members, community partners, and members of the oncology care team is demonstrated in professional and culturally acceptable behaviors.

Tasks:

- Identify resources and educational tools specific to shared decision-making that are pertinent to patient population, especially as it applies to advanced prostate cancer (*see Section III of this toolkit for the SHARE model used in clinical decision-making*)
- Collaborate with social workers and other mental health professionals to determine best practices in conflict management, emotional support, distress assessment and follow-up, etc
- Evaluate healthcare providers' preferences with respect to navigator involvement in shared decision-making; may be dependent upon scope of practice, education/licensure, resource availability, or other unique characteristics of the particular healthcare system.

References: 1. Baileys K, McMullen L, Lubejko B, et al. Nurse navigator core competencies: an update to reflect the evolution of the role. *Clin J Oncol Nurs.* 2018;22:272-281. 2. Strusowski T, Johnston D. AONN+ evidence-based oncology navigation metrics crosswalk with national oncology standards and indicators. *J Oncol Navig Surviv.* 2018;9:214-221. 3. American Cancer Society National Navigation Roundtable Training & Certification Working Group. *Navigator Core Competencies.* 2018. <https://navigationroundtable.org>. Accessed November 14, 2019. 4. Valverde PA, Burhansstipanov L, Patierno S, et al. Findings from the National Navigation Roundtable: a call for competency-based patient navigation training. *Cancer.* 2019 Sep 10. Epub ahead of print. doi: 10.1002/cncr.32470. 5. Johnston D, Sein E, Strusowski P. Standardized evidence-based oncology navigation metrics for all models: a powerful tool in assessing the value and impact of navigation programs. *J Oncol Navig Surviv.* 2017;8:220-237.

VII. BARRIERS TO CARE ALONG THE PATHWAYS

Addressing barriers to timely care is one of the core values of cancer navigation. These barriers can manifest in a variety of ways, either from the perspective of the patient and caregivers, or within the healthcare team, and may even extend into the healthcare system as a whole.

Barriers to Care Summarized

The following scenarios of different barriers can be classified based on whether the intervention is meant for the patient and family, or the intervention needed primarily focuses on the healthcare team or system (Table 1).

Fear/Anxiety Related to Advanced Cancer

Patient: *The more I learn about advanced prostate cancer, the more scared I feel. I was hoping they would talk more about curing the cancer, but it seems like the treatments will only temporarily hold things off.*

Providing perspective through education can allow navigators to have a positive impact on the barriers of fear and anxiety faced by patients and caregivers. What sounds like a very dire situation at first can be converted into a manageable one, simply by discussing what to expect over the coming months or years, however appropriate and realistic to the current clinical picture. Reducing fear and anxiety allows the navigator's follow-up messaging to fall on more receptive ears, giving more opportunity to tackle very difficult and demanding issues in the continuing care of advanced disease.

Psychosocial Issues (Financial, Emotional, Family Dynamics, etc)

Caregiver: *I think my husband is having a tough time going through chemotherapy, but he doesn't want to talk much about it. We're both pretty stressed given all these side effects, plus we received a letter from our insurance company—an explanation of benefits (EOB)—and it looks like we're going to need to pay quite a lot soon.*

Patients and their families/caregivers who face advanced prostate cancer are often met with multiple psychosocial stressors within a relatively short period of time, especially when patients have been newly diagnosed or as they proceed through intensive treatments. As a result, emotional and mental health

TABLE 1. Barriers to Care Summarized

Patient/family barriers to care
Fear/anxiety related to advanced cancer
Psychosocial issues (eg, financial, emotional, family dynamics, etc)
Insurance coverage/lack of comprehensive coverage to address all needed resources (Risk for Financial Toxicity)
Literacy and education (learning needs assessment)
Healthcare team or system barriers to care
Coordination of care among multiple departments within the facility
Coordination of care/referral patterns (or lack thereof)
Coordination of care across sites, including external referrals
Lack of time
Lack of educational resources for patients/providers
Cultural competency
Clinical trials (awareness, timely referral)
Resource allocation/gaps

Source: Pfizer. Metastatic breast cancer pathways: a resource guide for the navigator. April 2019. http://navigationroundtable.org/wp-content/uploads/metastatic_breast_cancer_manuscript_toc_link_04_03_19-1.pdf. Accessed November 11, 2019.

problems can frequently occur, and symptoms demonstrate differing levels of depression, adjustment disorders, anxiety, and even post-traumatic stress. Patients and their families/caregivers may express feelings of guilt, loss of control, anger, sadness, confusion, and fear.

In addition to these psychological issues, social problems can be intensified or initiated by the circumstances brought on by advanced prostate cancer. Social stressors commonly revolve around finances for these patients, related to aspects such as low income, cost of healthcare, lack of health insurance, or reduced employment/income.

In providing psychosocial support, navigators may first want to categorize the barriers identified to help guide an intervention. These barriers can fall into groupings such as¹:

- Insufficient logistical resources
 - Lack of transportation
 - Weak social support
- Lack of information, knowledge, and skills needed to manage the illness
- Inattention and lack of support from the healthcare system.

Navigators may recognize that they can assist with psychosocial barriers to some degree, provided they are within their scope of practice and expertise. However, they may also identify the need to defer to specialists.

Navigators may recognize that they can assist with psychosocial barriers to some degree, provided they are within their scope of practice and expertise, but they may also identify the need to defer to specialists, including mental health professionals, social workers, financial counselors, and support or advocacy groups, among others. Ongoing, continuous reevaluation of outcomes allows the navigator, along with the healthcare team, to tailor interventions in support of patients with advanced prostate cancer and their families.

Insurance Coverage/Lack of Comprehensive Coverage to Address All Needed Resources (Risk for Financial Toxicity)

***Caregiver:** We just received a letter from our healthcare insurance, and we're not sure if it's a bill or not. It says "evidence of benefits" at the top, then it shows quite a large amount of money for "patient responsibility" at the bottom. Are we going to have to pay that much? We're just getting started with the treatment plan, and insurance doesn't seem to cover much.*

Insurance coverage and a patient's out-of-pocket cost can be difficult to ascertain, given the spectrum of insurance benefit designs. Patients with seemingly full coverage are sometimes surprised by the actual bill for copayment when received. This problem becomes more severe for the uninsured and underinsured, posing system-level difficulties. Navigators can assist with this large-scale barrier through resource identification and referrals. Referral to social workers can help patients connect with financial assistance programs, either publicly funded or supported by industry, to minimize any out-of-pocket cost incurred. Referral to financial counselors can further minimize the patient's cost of care, since through their expertise, a wide variety of assistance programs can often be combined. In the absence of social work or financial counseling within the healthcare facility, navigators may need to address financial challenges directly, or refer out to community-based services, or even remotely based advocacy groups (*see Section XV of this toolkit*).

Literacy and Education (Learning Needs Assessment)

***Caregiver (patient's daughter):** Thank you for all the brochures and websites about what to expect with my dad's cancer treatment. I am actually having a bit of a hard time understanding everything, plus English isn't my dad's first language, so I wonder how much he really understands.*

Literacy is traditionally defined as the ability to read and write, whereas a broader interpretation of the term describes it as knowledge and competence in a specific area. For many patients and their caregivers, the language of cancer can seem very foreign, no matter the level of intelligence. Barriers to care may be as clear-cut as a language barrier but could also involve level of education or readiness to receive education, all of which can potentially be impaired by stress level, setting, or other physical/mental stressors.

To address barriers to literacy and education, navigators can start by assessing the learning needs of the patient (and caregiver), using the following considerations²:

- Find out what the patient wants and needs to know or do
- Learn what the patient already knows
- Discover what the patient is willing and able to learn
- Explore the patient's priorities
- Identify existing barriers to learning.

Navigators can address these types of barriers by using their skills and resources related to logistics.

In addition, navigators should ask themselves the following questions²:

- What is it that this patient specifically must know or do, and if he or she does not learn it, which life-threatening problems may occur?
- How is the information best delivered to the patient and any family members?
- When is the best time for the patient to learn?
- Where is the best place or setting for the patient to receive the instruction?
- Why does the patient need to know this?

Although the navigator can focus on assessment during the first meeting with the patient, the process should be included at each follow-up encounter, which may also include family members, caregivers, and other members of the healthcare team. Sharing the findings of multiple learning needs assessments among members of the healthcare team can collectively help reduce barriers to literacy and education for all involved.

Coordination of Care Among Multiple Departments within the Facility

Caregiver: *We have been given so many referrals. Medical oncology, radiation oncology, social worker... it's so overwhelming!*

Particularly following a new diagnosis of advanced prostate cancer, the patient is given multiple referrals within a short period of time. This can result in numerous appointments that require contacting and traveling to various departments, or even healthcare facilities, which can be very difficult for patients and caregivers to schedule, coordinate, and prioritize. Weaving all these clinical appointments into an already busy personal life (eg, work, care of children/grandchildren, social events, self-care) poses an additional challenge.

Navigators can address these types of barriers by using their skills and resources related to logistics. Types and timing of referrals can be well-anticipated by navigators, and the burden of scheduling can be shifted from patients and caregivers to the navigator. The work/life schedule can first be evaluated; then the navigator can assist in arranging all of the necessary appointments, perhaps even advocating on behalf of the patient for additional needs-specific referrals not yet initiated by other healthcare team members. Ideally, with the assistance of administrative staff, navigators (clinical and nonclinical) can present this completed timeline of events, or a checklist, for patients to best keep on track. Relatively simple interventions in logistics by the navigator can add greatly to the quality of life for patients and caregivers.

Coordination of Care/Referral Patterns (or Lack Thereof)

Urology nurse: *I remember when one of my patients learned of the new diagnosis of advanced prostate cancer a couple of weeks ago and was asking a lot of questions about radiation therapy and chemotherapy. It looks like there had been a consultation with one specialist but not the other, and the patient called me asking about the delay. Shouldn't it have happened by now?*

Given the many moving components involved in the dynamics of advanced prostate cancer, coordination of care can be compromised in a variety of ways. The healthcare team is ultimately responsible for making sure referrals are initiated and completed, yet the potential for pitfalls along the way

Navigators may not be able to fully remedy these barriers at the system level but can strategize on how to help patients maneuver these gaps.

remains, leading to untimely delays in the care of these patients. The clinical pathway may necessitate referrals to multiple medical specialties or supportive care services, as well as the patient's option for second-opinion visits among providers of a particular specialty. These referrals may not be made for any number of reasons, such as the preferences or biases of the referring provider or perhaps the difficulties in the logistics of referral (eg, scheduling, transportation, or communication deficiencies). A multidisciplinary care team is best positioned to address some of these coordination issues, but sometimes patients and caregivers get caught up in what seems—to them—a whirlwind of events.

Navigators can help relieve the distress that can be associated with this type of situation, guiding patients and caregivers through the process. Navigators are equipped to assist with logistical issues, facilitating any referrals ordered on behalf of the patient. Regardless of provider preferences, referrals to all appropriate specialties, including second opinions, will help the patient make well-informed decisions about their plan of care. Although most navigators may not have the authority to order such referrals, they can inform and advocate for the patient to pursue these visits within their own best interest, either through their treating physician or primary care provider, or another authorized clinician. Navigators can also work with fellow healthcare providers to identify any gaps or deficiencies in the referral process. Troubleshooting and streamlining referral processes can have a positive impact on the entire population of patients with advanced prostate cancer, by ensuring that they are properly served by their healthcare team moving forward.

Coordination of Care Across Sites, Including External Referrals

Caregiver: *We had a long discussion about the patient's life goals, and it sounds like the patient wants to finally learn more about palliative care and hospice at this point. It appears that these options exist here at the facility, but there seems to be several services in the community that might also be helpful. Can you help look into all of these?*

As already discussed, deficiencies in the coordination of care can be dependent on the individual patient and their caregiver—or with the healthcare team or within the particular facility—but can also reveal problems at the system level, including referrals to other facilities or community resources. Navigators may not be able to fully remedy these barriers at the system level but can strategize on how to help patients maneuver these gaps. In some systems, navigators can connect with fellow navigators or resource staff, at facilities external to their own.

Navigators can form working relationships with key people in frequently used disciplines for patients with advanced prostate cancer, such as urology, medical oncology, and radiation oncology, as well as palliative care and hospice. In some healthcare systems, these disciplines can be based at separate healthcare

facilities altogether, or perhaps as independent services in the community or in private practice. The role of the navigator focuses on optimizing care transitions within the care plan, not only per each individual case of advanced prostate cancer, but also by streamlining and troubleshooting the steps needed in these transitions, so that a smooth, effortless process is perceived from a patient and family perspective. At an advanced level of navigation, service agreements and outcomes measures can be implemented to aid in process improvement overall. For consistency, navigators may take primary responsibility for certain types of referrals, which is especially helpful for those transitions that are relatively rare or complex.

Lack of Time

Oncology nurse practitioner: *I just saw a patient for a follow-up appointment regarding the hormone treatment that was started for bone metastasis. We probably needed more time together, but most of the patient's questions were about the upcoming radiation treatments.*

Lack of time from the perspective of a healthcare provider is a prevalent problem and can be a result of high demands coupled with limited resources, as well as other responsibilities outside of direct patient encounters, such as documentation and administrative duties. Issues that patients want to address during their visit may fall outside the expertise of the provider being seen, given the multifaceted nature of care

for patients with advanced prostate cancer.

Navigators can help address this barrier to care through an initial learning needs assessment of the patient population they serve, perhaps focusing on one medication, intervention, or other expected aspect of care.

Navigators can support fellow healthcare providers indirectly by obtaining thorough learning needs assessments for patients early in the diagnosis process and providing coordinated education and resources, in an effort to answer baseline questions. Giving patients a strong knowledge database as

a foundation can reduce time used by other providers to address these issues, so that they may instead focus on specialty-specific concepts. Navigators can also position themselves as an on-demand resource of information available throughout the care continuum, whereby patients and caregivers can reach out for advice or resource identification, and providers can refer patients to navigators for follow-up on specific issues, within the scope of practice. Questions that were once directed to treating physicians and nurses can begin to be addressed by the navigator, who acts as a liaison, focusing on education and advocacy. In this way, fellow clinical healthcare providers benefit by being able to dedicate their time to clinical tasks.

Lack of Educational Resources for Patients/Providers

Patient: *About that new medication I'll be starting soon...I looked it up online and found a lot of information about it, but I'm not sure what really pertains to me. There's got to be at least 10 websites in this one list.*

With today's easy accessibility to information, the problem is not so much about lack of educational resources, but more about finding the right resources that are valid and pertinent to the patient with advanced prostate cancer. Patients who search for information on their own may meet with more confusion than clarity.

Navigators can help address this barrier to care through an initial learning needs assessment of the patient population they serve, perhaps focusing on one medication, intervention, or other expected aspect of care. An evaluation of available educational resources can be conducted, in collaboration with key members of the healthcare team. This can help to develop a set of vetted educational tools that can be shared with patients and their caregivers, providing a consistent message from the healthcare team in support of quality cancer care.

Cultural Competency

Oncologist (to navigator): *I just met with Mr F regarding chemotherapy for his advanced prostate cancer. We couldn't get an interpreter there, but his daughter was able to translate. I wonder how much they really understood about the plan.*

Cultural barriers to care can arise as a result of race or ethnicity but may also stem from other factors such as religion, socioeconomic status, or another source of disparity. Culturally competent care necessitates a working knowledge and understanding of the patient's background; the healthcare team may want to identify the most common ethnic, racial, or cultural groups served in the region, so that strategies can be put into place prior to having patients entered into the system. Communication and language barriers can affect the relationship between patients and providers. Trained medical interpreters must be used whenever possible versus family or caregivers, who may have limited understanding of the disease and treatment or may feel compelled to protect the patient from any bad news.

As part of the healthcare team, navigators can begin with simple practical interventions, such as asking about language preference and arranging for interpreter services or inquiring with patients or family members about their beliefs and practices that may come into play during their cancer care. Patients and their families can also be encouraged to incorporate cultural, religious, and healing practices into the patient's care plan, giving them a more active role. Resources on providing culturally competent care should be made readily available to the healthcare team, so that care can quickly be adapted as necessary.

Clinical Trials (Awareness, Timely Referral)

(See also Section II in this toolkit, regarding barriers to clinical trials and corresponding navigator skills that may be used to address these barriers.)

Patients with advanced prostate cancer frequently are eligible for clinical trials, yet some may not be enrolled due to a variety of issues such as educational gaps, social, logistical gaps. Decisions about cancer treatment are already complex, so the idea of adding clinical trial participation can be daunting to many patients, caregivers, and healthcare providers. Even in the absence of barriers, patients' own attitudes about clinical trials may prevent participation; for example, personal preference for treatment may be overridden in a randomized trial, or a patient's fear or mistrust of medical research may be enough for them to avoid enrolling in a clinical trial.

Navigators can collaborate with clinical trial nurses and their physician primary investigators, making sure that patients are evaluated by the research team to identify eligibility. In some cases, the nurse navigator may be responsible for screening patients for clinical trials. Patients can be referred for educational visits with the clinical trials nurse, to gain a thorough review of the pros and cons of clinical trial participation. Patients can then make an informed decision and have a discussion with their physician about whether to proceed.

Resource Allocation/Gaps

Across the United States, there is an ever-growing demand for cancer care, and the healthcare system's ability to meet the need is in crisis, with more complex treatment, a shrinking workforce, and rising costs.³ Navigating patients with advanced prostate cancer may require using resources not only from within the healthcare facility itself, but also external facilities system-wide, to best serve all identified needs. Navigators may need to develop workarounds for any gaps and barriers in the prescribed course of cancer care. For a more long-lasting impact, navigators can collaborate with administrators, physicians, and other key stakeholders, perhaps on a committee or task force aimed at making system-wide changes.

References: 1. Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press; 2007. 2. The Ohio State University College of Medicine. *Getting Your Message Across: Clear and Effective Health Communication*. <https://healthliteracy.osu.edu/modules/5>. Accessed July 22, 2019. 3. Institute of Medicine. *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. Washington, DC: National Academies Press; 2013.

VIII. DISTRESS SPECIFIC TO ADVANCED PROSTATE CANCER

Coping with advanced cancer can be hindered by a variety of issues, ranging from the physical and practical, to the spiritual, social, and psychological (cognitive, behavioral, emotional), adding to the unpleasant experience of the disease. The National Comprehensive Cancer Network Distress Thermometer is widely used in cancer care practice, for initial assessment of distress as well as periodic reevaluation, ideally at every medical visit.¹ (See also *General Navigation Toolkit, Section VIII, “Distress and Psychosocial Needs.”*)

Patients and caregivers dealing with advanced prostate cancer are at high risk for distress, by nature of the disease alone. Upon discovery of advanced disease, these individuals can have periods of increased vulnerability as they learn more about the stage and grade of the patient’s cancer in diagnostic workup,

Navigators can help administer distress tools to patients and caregivers, providing opportunities to address any troublesome issues promptly throughout the care continuum.

make decisions regarding the treatment plan and await its start, and perhaps educate themselves about genetic and familial risk. Frequent distress assessments should continue well into treatment, to parallel the increasing burden of symptoms and complications that are possible, as well as the need for many different, sometimes concurrent, treatment modalities. With possibly fewer in-person visits to the care center, distress assessment and management should continue during any breaks in treatment into post-therapy monitoring, perhaps aided by using the Distress Thermometer and other tools by telephone or electronically.

Separate from the cancer care plan, other risk factors for distress can contribute to the situation. For example, men may be less likely to reach out for help when facing cancer, as opposed to women, who may be more interdependent, seeking support from family and caregivers or participating in peer support groups.

Navigators can help administer distress tools to patients and caregivers, providing opportunities to address any troublesome issues promptly throughout the care continuum. Even if the Distress Thermometer reveals minimal distress not requiring referral, it opens up lines of communication, allowing all involved to verbalize how they are coping with the current situation and if there are any concerns that can be addressed by the navigator and the primary cancer care team.

Navigator Interventions for Expected Distress Symptoms

Some anticipated symptoms of mild distress (Distress Thermometer <4) can be appropriately managed by the primary oncology care team, which typically includes the navigator. Referrals may be needed for Distress Thermometer scores of ≥4. Expected distress symptoms may include¹:

- Fear and worry about the future
- Anger, feeling out of control
- Erratic sleep patterns
- Poor appetite
- Concerns about social role (ie, as father, mother)
- Financial concerns.

Table 1 shows the types of interventions recommended with some specific examples pertinent to Mr Powers and similar patients and caregivers dealing with advanced prostate cancer.

TABLE 1. Examples of Interventions for Navigators Specific to Patients with Advanced Prostate Cancer

Intervention	Example
Assessment	Complete Distress Thermometer at each visit and outline options for support
Planning	Based upon known staging and grading, educate patient/caregiver on possible clinical pathways and what might be expected with each Confirm treatment plan with primary oncology care team (eg, physicians, nurses) Begin discussion of advanced care planning and consider referral to social work
Shared decision-making	Review planned treatment and identify point where new modalities may start or decision points that need to be addressed (eg, many options in systemic treatment for mCRPC)
Coordination	Maintain ongoing communication with patients, caregivers, and oncology care team Share findings of assessments completed with the care team
Support services	Referrals as needed to social work, genetic counseling, financial navigation, community resources, peer support Identify support groups (eg, in-facility, community, or online/national advocacy groups) Referrals to social work or mental health counseling Identify community resources that offer exercise programs geared toward patients with cancer Refer for physical therapy and evaluation as appropriate
Caregiver support	Offer support to patients and caregivers Referral to family counseling Referral to social work or mental health counseling
Spiritual support	Referral to chaplain Identify patient's preferred spiritual support (eg, churches, religion)

mCRPC indicates metastatic castration-resistant prostate cancer.

Case Study on Distress with Mr Powers, Diagnosed with Advanced Prostate Cancer

The following case study has been adapted from *The Case of Mr Powers' Prostate Cancer Recurrence*, a module presented by the American Urological Association on prostate cancer management.² It has been modified to show the impact of navigation on distress management.

Prostate Cancer Recurrence: A Case Study. Mr Powers is a young appearing, healthy 68-year-old male who underwent a radical prostatectomy 9 years ago for early-stage prostate cancer (Gleason 6). He now has evidence of prostate cancer recurrence.

Mr Powers and his wife of 40 years have spent the past several years traveling the world and enjoying themselves. Although his initial prostate-specific antigen (PSA) level was undetectable the first year, it began to rise slowly after that. He suffered moderate erectile dysfunction following the procedure but had a full recovery. Unfortunately, his jet-setting lifestyle has filled up his schedule and he was lost to follow-up.

On a recent visit with his healthcare provider, his PSA level is checked and comes back as 6 ng/mL. Mr Powers now has evidence of prostate cancer recurrence, although he reports no urinary problems and no bone pain. On physical examination, the prostate bed is empty on digital rectal examination (as would be expected), and he reports satisfaction with erectile function and sexual health. Baseline bone scan is negative.

Mr Powers' PSA level falls dramatically after his first injection of a luteinizing hormone–releasing hormone agonist. Once again, he makes travel plans including his wife, daughter, and newly married son. Mr Powers comes in every 3 months for this injection, and his PSA level is followed closely. He now meets regularly with

the prostate cancer nurse navigator, immediately after his periodic injections. As part of ongoing assessments, the navigator administers the Distress Thermometer tool at each session. Distress Thermometer scores have remained steady at 2 to 3, but his wife is visibly more nervous at each visit. The navigator has a thorough discussion of the tool findings, and they agree that a referral to a social worker would be helpful to assess the psychosocial needs of both Mr and Mrs Powers.

Unfortunately, 1 year later, his PSA is rising, and although a bone scan shows metastatic disease to the bone, Mr Powers has minimal pain at this point. Biopsy of 1 bone lesion was sent for genomic analysis, and genetic counseling and testing were completed. Neither high microsatellite instability (MSI-H) nor deficiency in mismatch repair genes (dMMR) were found in the genetic analysis of the biopsy, but germline genetic testing revealed a *BRCA2* mutation. He will be meeting with the medical oncologist next week to discuss systemic therapies. Mr Powers and his wife once again discuss the plan with the nurse navigator. Mrs Powers also mentions that she just enrolled for Medicare herself, and they are looking at the options in supplemental plans that may be best for them both. She also worries about her daughter's cancer risk, given the mutation found in Mr Powers. His last Distress Thermometer scored 4 on a scale of 0 to 10, and he was mainly worried about his children and the impact of future treatments. With this new concern regarding finance and insurance, the navigator will connect with the social worker to see what can be done. Given the complexities of Medicare supplemental plans, referral to the financial navigator is also offered by the nurse navigator.

Once the cancer is confirmed to be advanced with the positive bone scan, the patient navigator plans monthly check-ins, either by phone or in person, to increase the frequency of assessment—including the Distress Thermometer—to ensure interventions happen in a timely and thorough fashion. With a biopsy negative for MSI-H and dMMR, a checkpoint inhibitor is eliminated as a systemic treatment option, yet many other options are on the table, to be discussed in detail with the medical oncologist. Based on the medical oncologist's consult note, the navigator prepares specific educational materials regarding potential treatment options for Mr Powers. The navigator meets with the medical oncologist and her nurse regarding logistical issues and expected outcomes for these treatment choices.

Treatment decision-making can be very complex here, in consideration of a variety of hormone management therapies, chemotherapies, and immunotherapies; there is currently no firm consensus on sequencing of these agents. With a *BRCA2* mutation found, the navigator can work with genetic professionals to help deliver education to Mr Powers about hereditary breast and ovarian cancer syndrome, and how it may impact his own treatment (consider clinical trials for poly (ADP-ribose) polymerase inhibitors—refer to the clinical trials coordinator), as well as his family's possible inherited risk for cancer. Mr Powers' adult children and his own siblings should be seen by genetic counseling for a thorough cancer risk assessment. If they are found to also carry the *BRCA2* mutation, Mr Powers' daughter may need high-risk breast and ovarian cancer screening and his son may need earlier and more intensive prostate cancer screening (and possibly breast cancer screening). All may need to be followed within a high-risk clinic or research study for the risk of pancreatic cancer and/or melanoma.

Distress assessment is an essential tool for navigators to use with patients and their families who are dealing with advanced prostate cancer. Multiple interventions that optimize quality of life can stem from just one proper administration of the Distress Thermometer tool. Ongoing assessment by navigators and the oncology care team is key to proper management of distress, especially in cases of advanced prostate cancer, where needs can fluctuate greatly for all involved. The patient may need to be referred to a psychotherapist or family counselor. There are cases when a psychiatrist is needed for more aggressive interventions. If a patient is referred for further counseling, it is important to follow up to make sure the appointment is kept.

Navigators should consider asking the “Navigator Questions” again (see *Section I of this toolkit*), as they are very much tied to learning more about any of the patient's concerns.



IX. PUTTING IT ALL TOGETHER: CONTINUUM OF CARE FOR PATIENTS WITH ADVANCED PROSTATE CANCER

Continuum of Care in Advanced Prostate Cancer

Men enter the realm of advanced prostate cancer by way of 2 tracks. First, there are those who have been previously diagnosed and treated for clinically localized disease, which has now progressed to recurrent advanced disease. Second, there are people whose first encounter with prostate cancer is at an advanced stage, with nodal and/or metastatic involvement at the onset.

Navigators accompany patients with advanced prostate cancer and their families along this journey, which can take a very difficult course through the stressful times of diagnostic workup and monitoring. In addition, they help to overcome a number of potential barriers to care as they occur, all while the patient is undergoing a variety of daunting, innovative treatments. At each step of the continuum of care, navigators have a good opportunity to actively make the process better, by optimizing the quality of life for all involved, including patients, families, caregivers, and fellow healthcare providers.

Mr Powers' Prostate Cancer Recurrence Revisited and Expanded

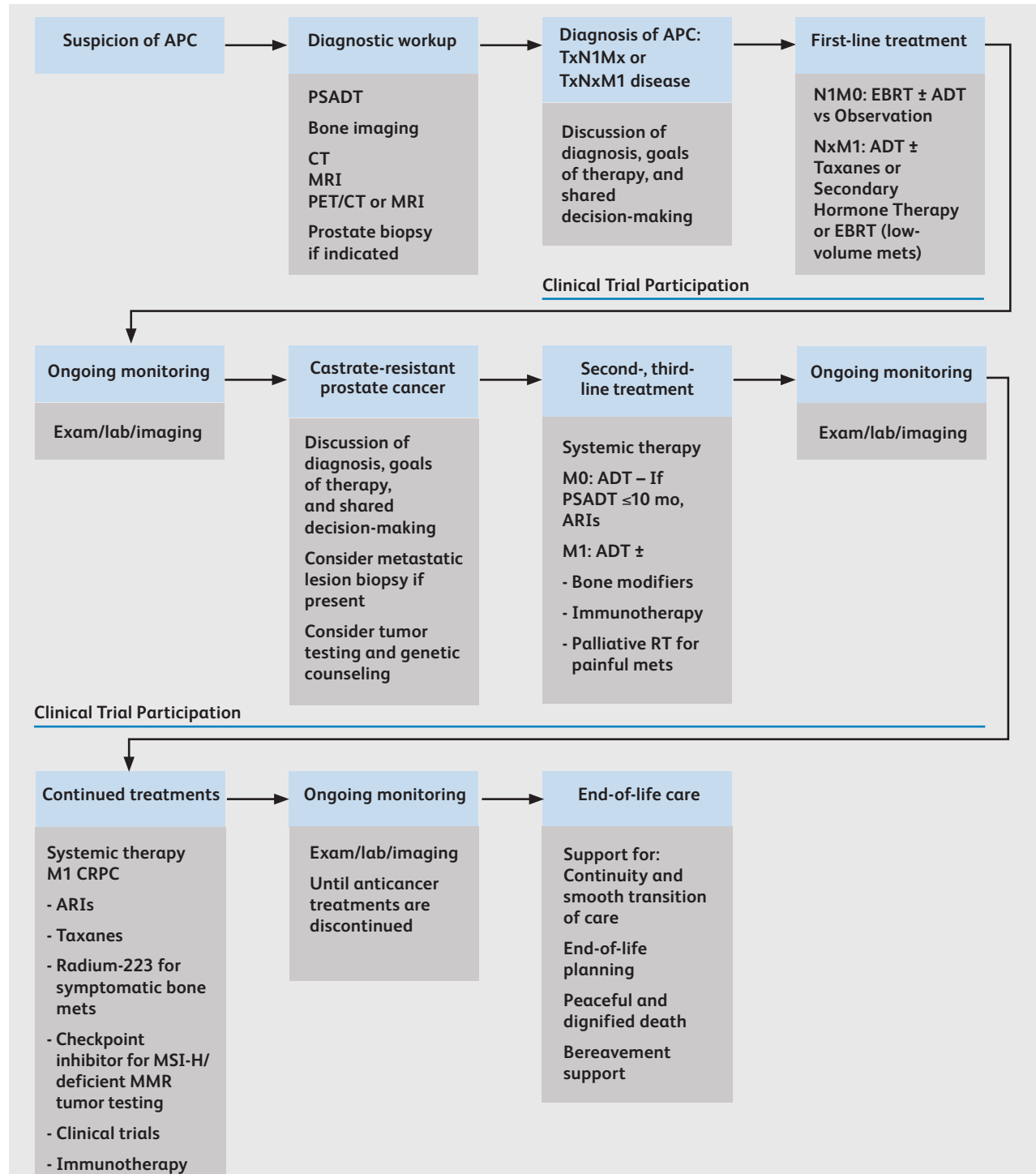
The case of Mr Powers, who was diagnosed with advanced prostate cancer, was presented earlier in this toolkit in Section VIII, with a focus on distress management. As depicted in **Figure 1**, we can revisit Mr Powers as he moves into the clinical pathway for advanced prostate cancer, as well as into end-of-life care. Within each step, the navigator can contribute to overall quality of life through interventions directed specifically to the patient and family.

The following case study has been adapted from *The Case of Mr Powers' Prostate Cancer Recurrence*, a module presented by the American Urological Association on prostate cancer management.¹ It has been modified to show the impact of navigation.

To recap, Mr Powers is a 68-year-old male who underwent a radical prostatectomy 9 years ago. After being lost to follow-up for several years, he presented with a high prostate-specific antigen (PSA) level of 6. Hormone therapy was started, yet now a year later, his bone scan is positive for bone metastasis, but with minimal pain. Biopsy of 1 bone lesion was sent for genomic analysis, and genetic counseling and testing were completed. Neither high microsatellite instability nor deficiency in mismatch repair genes were found in the biopsy tissue, but genetic testing revealed a *BRCA2* mutation. Recently, he met with the medical oncologist to discuss several options for additional systemic therapies, including immunotherapy, taxane-based chemotherapy, and androgen-receptor-based therapies (biosynthesis inhibitors or receptor inhibitors). Bone health was also reviewed along with the use of a receptor activator of nuclear factor- κ B ligand inhibitor, plus the need to maintain calcium and vitamin D levels to keep bones strong in the face of androgen-deprivation therapy. Given the *BRCA2* mutation, clinical trials for poly (ADP-ribose) polymerase inhibitors were discussed, and may be an option down the line.

Mr Powers and his wife came in today to discuss the plan with the navigator. They both seem to be overwhelmed with everything. Mrs Powers mentions that she just enrolled herself in Medicare, and the couple is looking over the options in supplemental plans that may be best for them both. She is also worried about her daughter's cancer risk, given the mutation found in Mr Powers. His last Distress Thermometer scored 4 on a scale of 0 to 10, and he was mainly worried about his children and the impact of future treatments.

FIGURE 1. The Care Continuum for Mr Powers and the APC Navigator

**Clinical Trial Participation**

ADT indicates androgen-deprivation therapy; APC, advanced prostate cancer; ARI, androgen receptor inhibitor; CRPC, castration-resistant prostate cancer; CT, computed tomography; EBRT, external beam radiotherapy; mets, metastasis; MMR, mismatch repair; MRI, magnetic resonance imaging; MSI-H, microsatellite instability-high; PET, positron emission tomography; PSADT, prostate-specific antigen doubling time; RT, radiation therapy.

Adapted from Pfizer Oncology. Metastatic breast cancer pathways: a resource guide. http://navigationroundtable.org/wp-content/uploads/metastatic_breast_cancer_manuscript_toc_link_04_03_19-1.pdf.

Stepping Through the Care Continuum with the Navigator

As depicted in Figure 1, there are distinct steps in the care continuum for advanced prostate cancer, whereby the navigator can play an active role in guiding Mr and Mrs Powers smoothly through the process. With the initial suspicion of advanced prostate cancer, the navigator has the opportunity to ask specific questions, not only to assess the patient's and family's understanding of the disease, but also to begin building a trusting relationship and explore their life goals.² (*See the questions/inquiries outlined in Section I of this toolkit.*)

By having these candid conversations early and often, the navigator can best advocate for Mr and Mrs Powers to help them reach their goals. Using the responses to questions such as these, the navigator can provide patient-centered education and interventions.

After suspicion of advanced prostate cancer is confirmed, diagnostic workup is the next phase of care, to gather more information about the disease and determine a treatment plan. During this phase, the multiple tests and procedures ordered can increase the level of distress for Mr and Mrs Powers, especially given all the unknowns. In Mr Powers' case, a high PSA level led to a bone scan (and potentially further imaging with computed tomography or positron emission tomography/computed tomography) and a bone biopsy to gather tissue for pathologic and genomic analyses; genetic counseling and germline genetic testing were also completed. Navigators must address many "what if" questions from patients and families, while awaiting diagnostic testing results. At these educational encounters with Mr and Mrs Powers, the navigator can also take the opportunity to administer the Distress Thermometer tool, to assess how they are coping with the current situation, and perhaps uncover and address underlying issues.

In Mr Powers' case, concerns were revealed regarding his children's potential cancer risk, given the genetic counseling and germline testing. Financial concerns regarding insurance also became apparent. Thorough assessment can assist the navigator in prioritizing concerns to address for Mr and Mrs Powers. If financial and family issues are primarily on their minds and remain unaddressed, it may be more difficult to teach them about what to expect regarding diagnostic tests and treatment decision-making. Navigators can provide patient support and direct counseling for these concerns first, or refer them to the social worker, financial navigator, or other support services.

Once the diagnostic workup is completed, Mr and Mrs Powers' attention now turns to treatment decision-making and planning. With a confirmed distant bone metastasis, Mr Powers continues androgen-deprivation therapy, but the next question is which additional therapies can be used, namely, taxane-based chemotherapy versus androgen receptor inhibitors. There may even be a role for external beam radiation therapy, if the bone metastasis is isolated and low volume. After an initial consultation with the medical oncologist, another meeting with the navigator can be useful for Mr Powers to revisit all the pros and cons of each option. To gather additional information, further consultations may be arranged with a radiation oncologist, or even second-opinion visits with another medical oncologist. *As outlined in Section III of this toolkit*, the SHARE approach to clinical decision-making can help greatly with this process, allowing Mr Powers to become confident in his treatment decisions.

If the diagnostic workup reveals that Mr Powers is eligible for 1 or more clinical trials geared toward patients with advanced prostate cancer, the navigator can facilitate a referral to a clinical trials coordinator for a thorough evaluation. A referral to palliative care is also appropriate at this time, to promote relief of distress, provide psychosocial/spiritual support, and assist with management of any side effects that occur with treatment.

Once these first-line treatments are completed, ongoing monitoring and supportive care become the focus for Mr Powers and his family, along with the navigator. Anticipating the results of laboratory tests, imaging, and physical examinations can be a stressful time for Mr and Mrs Powers, who stand by their

hope that treatments are a success. Now that there is a treatment “holiday,” Mr Powers agrees to connect with the navigator either in person or by phone or e-mail, at least monthly, in addition to his scheduled clinical follow-up appointments with his physician. The navigator can use these monthly opportunities to administer quality-of-life assessment tools, such as the Expanded Prostate Cancer Index Composite for Clinical Practice (*see Section III of this toolkit*) or the Edmonton Symptom Assessment System (*see Section XI of this toolkit*), and also take time to provide psychosocial support as needed.

If monitoring reveals findings that need further treatment, the navigator can help Mr Powers transition into second-line treatments, further monitoring, and supportive care. In a cyclical fashion, the navigator can continue to check in with Mr Powers and his family on a monthly or more frequent basis, as anticancer treatments continue along with subsequent follow-up monitoring.

Ultimately, there is a transition from anticancer treatments and palliative care to end-of-life care. Navigators can best assist with this transition by having a thorough understanding of the concept of hope. The 6 circles of hope provide a framework for navigators to help guide this transition (ideally in collaboration with the palliative care team), so patients and families can more concretely define their goals of care²:

- Hope for a cure
- Hope for a sudden and long remission of disease
- Hope for a pain-free existence
- Hope for the resolution of interpersonal relationships
- Hope for forgiveness
- Hope to be remembered well.

Focusing on Mr and Mrs Powers’ goals of care is key for the navigator, who should actively work with them to creatively fulfill these hopes, sometimes in alternative ways (eg, letter writing, cards for children/grandchildren around specific milestones, or other ways to establish a lasting presence).

As Mr Powers transitions into end of life and hospice care, the final hope to fulfill is to have a peaceful death. The major components of a good death include²:

- Management of pain and suffering (current control and control of future symptoms)
- Clear decision-making (making preferences known to the patient’s physician and healthcare team in advance)
- Preparation for death (logistics, or understanding the physical/psychosocial changes to come)
- Completion (issues of faith, life review, resolving conflicts, saying goodbye)
- Contributing to others (gifts, time, or knowledge).

Navigating Mr Powers through the circles of hope, into a good and peaceful death, and supporting Mrs Powers and family with bereavement care, are some of the most significant roles that a navigator, social worker, and/or chaplain can perform in providing quality end-of-life cancer care.²

References: 1. Amiel G, Hollis M, Kreshover J, Terris M. Medical Student Curriculum: Prostate Cancer Screening and Management. www.aunet.org/education/auauniversity/for-medical-students/medical-student-curriculum/prostate-cancer/psa. Accessed July 22, 2019. 2. Shockney LD. Fulfilling Hope: Supporting the Needs of Patients with Advanced Cancers. Hauppauge, NY: Nova Science; 2014.

X. GENETIC/GENOMIC TESTING

All malignancies begin as a result of gene mutations in an individual's DNA, which can lead to a state of uncontrolled cell proliferation. Basically, there are 2 types of genetic mutations—somatic mutations and germline mutations. Somatic mutations most commonly cause cancer and are the result of damage to a particular cell during one's lifetime. Randomly, or because of external or environmental factors, these DNA changes can accumulate as the damaged cell proliferates, creating an abnormal mass, or tumor. Somatic mutations are not included in the DNA that is passed from parent to child. Some known risk factors for somatic mutations include: (1) tobacco, (2) ultraviolet radiation, (3) viruses, and (4) age.¹

Germline mutations, in contrast, do pass from parent to child at the time of conception, with this type of mutation occurring in a sperm cell or an egg cell.¹ Germline mutations are much less common than somatic mutations.

As the embryo develops, the mutation is copied into every cell of the body.

Accounting for approximately 5% to 20% of all cancers, germline mutations are linked to hereditary cancer and can pass from generation to generation,

with rates that are often much higher than those associated with sporadic (noninherited) cancer and familial cancer.^{1,2} In patients with prostate cancer, the incidence of germline mutations is estimated to be 4.6% in patients with localized disease and 11.8% to 16.2% among those with metastatic disease.³

Prostate cancer has more recently been evaluated with respect to hereditary cancer syndromes, including hereditary breast and ovarian cancer (HBOC) syndrome and Lynch syndrome. Advances in tissue genomic analysis have also made available several tests that are searching for acquired, or somatic, mutations in the tumors themselves, to assist further in clinical treatment decision-making. With a working knowledge of prostate cancer genetics, navigators can provide well-informed support and education for patients with advanced prostate cancer and their families, ideally optimizing referrals to genetics professionals for specialized interventions.

Germline Testing

Patients with advanced prostate cancer may be eligible for genetic counseling and considered for genetic testing, based on the stage and the grade of their disease, the patient's age at diagnosis, and any family history. Genetic testing for mutations in germline DNA is usually performed on a blood, saliva, or tissue biopsy sample. Given the complexities surrounding the implications of the test, genetic counseling is a preferred first step in pursuing germline genetic testing.

Testing Criteria/Insurance Coverage

Clinical testing criteria provide conventional guidance regarding which patients are eligible for specific genetic testing, as it pertains to prostate cancer. For patients with a personal history of disease, they may meet the criteria for *BRCA1*- and *BRCA2*-based genetic testing, as related to the HBOC syndrome, as follows⁴:

- Personal history of metastatic prostate cancer, regardless of family history
- Personal history of high-grade prostate cancer (Gleason score ≥ 7) at any age with
 - ≥ 1 close blood relatives with ovarian, pancreatic, or metastatic prostate cancer at any age or breast cancer at <50 years of age; or

In patients with prostate cancer, the incidence of germline mutations is estimated to be 4.6% in patients with localized disease and 11.8% to 16.2% among those with metastatic disease.

- ≥2 close blood relatives with breast or prostate cancer (any grade) at any age; or
- Ashkenazi Jewish ancestry.

Since most insurance carriers support these guidelines, if criteria are met, then coverage for genetic testing is available. Actual out-of-pocket test costs may vary based on laboratory used, individual insurance plan, or patient's unmet deductible; this should be discussed in detail with the patient by the genetic counselor or the financial navigator prior to submitting a sample for genetic testing.

Outside of HBOC syndrome, patients with advanced prostate cancer may have access to germline testing by other methods. For patients with appropriate stage and grade of advanced prostate cancer, tissue-based somatic testing of prostate tumor tissue can reveal acquired mutations that provide access to germline genetic testing. For example, if tumor testing reveals a deficient mismatch repair (dMMR) gene, germline genetic testing for Lynch syndrome genes is recommended.

Gene Panels

Most clinically available cancer genetic tests include *BRCA1/2* within a multigene panel that contains a variety of genes with some relation to the types of cancer found in the patient and his or her family. For prostate cancer, the National Comprehensive Cancer Network (NCCN) guidelines recommend that, at a minimum, a panel should include analysis of the following genes: *BRCA1*, *BRCA2*, *ATM*, *CHEK2*, *PALB2*, *MLH1*, *MSH2*, *MSH6*, and *PMS2*.⁵ Other genes may be considered as well, depending on the clinical picture. Most genes on these panels have clinical implications for screening and management of cancer, but other genes may not yet have any suggested intervention, based on limited available data at this time. For example, in patients with prostate cancer, *HOXB13* is regularly included in gene panels as a prostate cancer risk gene,⁵ but it does not have current implications in the advanced disease setting. Genetic counseling can help assess what level of genetic testing is appropriate; clinical actionability should be a primary concern, rather than the quantity of genes in the panel.

Implications of Germline Testing

Sporadic risk for cancer is thought to be related to acquired mutations, resulting from random changes in dividing cells in a particular organ, such as the prostate gland, as well as from environmental or otherwise unknown risk factors. Genetic, or hereditary, cancer risk is associated with a germline mutation, already present at birth and inherited from a parent or parents, with the mutation present in all cells. In familial risk, a particular type of cancer occurs with greater frequency within a given family compared with that observed in the general population, although no specific gene mutation has been identified. An estimated 5% of all prostate cancers are thought to result from high-risk genetic mutations, whereas about 75% are sporadic and the remaining 20% are attributed primarily to familial risk.⁶

If germline testing reveals a mutation, the genetic risk for selected cancers is expected to be much higher than familial and sporadic risk.

If germline testing reveals a mutation, the genetic risk for selected cancers is expected to be much higher than familial and sporadic risk. Depending on the gene involved, clinical guidelines may warrant high-risk screening and preventive measures for those types of cancer that might not otherwise have been considered based on clinical history alone. For individuals who already have a personal history of cancer, treatment and management plans may need to be modified as well. Details on gene-specific management are outlined in the NCCN Guidelines, which are available online.⁴ For example, patients with advanced prostate cancer who are found to carry a *BRCA1/2* mutation can pass this on to their children, for whom high-risk breast and ovarian cancer screening and preventive measures are then

necessary. Genetic counselors routinely collaborate with oncology physicians and nurse specialists to make certain that these interventions are carried out for patients and their families. Navigators can also play a key role in ensuring appropriate care and follow-up with respect to cancer genetics.

Somatic Tissue Testing

Tissue-based somatic testing is an emerging field in prostate cancer, potentially affecting treatment options for patients with advanced disease. Somatic mutations may reveal a risk for a germline mutation, leading to blood- or saliva-based testing, but it is not a direct correlation. An estimated 89% of metastatic castration-resistant prostate cancer tumors contain a clinically actionable mutation, but only 8% of these had corresponding mutations in the germline.⁷ The NCCN has guidelines for somatic testing in patients with prostate cancer, based on risk groups, as follows⁵:

- Tumor testing for somatic homologous recombination gene mutations (eg, *BRCA1*, *BRCA2*, *ATM*, *PALB2*, *FANCA*, *RAD51D*, and *CHEK2*) can be considered in patients with regional or metastatic prostate cancer
- Tumor testing for microsatellite instability (MSI) or dMMR genes can be considered in patients with regional or metastatic prostate cancer
- Multigene molecular testing can be considered for patients with low- and favorable-intermediate-risk prostate cancer and a life expectancy of ≥ 10 years
- The Decipher molecular assay can be considered as part of counseling for risk stratification in patients with prostate-specific antigen (PSA) resistance/recurrence following a radical prostatectomy.

Tissue-based somatic testing is an emerging field in prostate cancer, potentially affecting treatment options for patients with advanced disease.

Outside of these guidelines, patients with advanced prostate cancer may have access to additional broad genomic profiling tests, to help determine eligibility for novel therapies based on their results. Patients should discuss these options with their treating physician, as the criteria for testing in this arena are not as well-defined.

Insurance coverage is variable with broader panels, and cases may exist in which out-of-pocket costs are inexplicably lower without insurance, given various patient protection and self-pay programs offered through genetic laboratories.

Impact on Treatment and Clinical Decision-Making

Results from somatic tissue genetic analysis may lead to specific interventions for patients with advanced prostate cancer. If mutations are found in the homologous recombination genes, genetic counseling and testing may be considered in patients who have not yet completed germline testing. Poly (ADP-ribose) polymerase inhibitors are a class of drugs that are used in those patients with breast and ovarian cancer who carry germline or somatic mutations, including *BRCA1/2*. Clinical trials are currently underway to investigate whether patients with metastatic castration-resistant prostate cancer who are carriers of gene mutations may respond well to this type of therapy.⁸

With tumor testing for MSI or dMMR, patients may be eligible for treatment with a monoclonal antibody/programmed death 1 checkpoint inhibitor, if tissue is found to be MSI-high or dMMR-positive (ie, deficient for mismatch repair, as detected by immunochemistry). Decipher molecular assay results of the post-prostatectomy specimen can help patients and providers decide between observation/PSA monitoring and adjuvant/early radiation following surgery, given PSA persistence after prostatectomy.

In broad genetic profiling of prostate cancer, data are preliminary, but genomic alterations were found in multiple cell pathways that may indicate a response to specific targeted therapies in 57% of those cases tested.⁹ Clinical trials should be considered that explore those novel therapies in development, to provide access to patients with advanced prostate cancer, as appropriate.

Defining the Navigator's Role in Genetics/Genomics

Understanding what is available in terms of genetics and genomics for patients with advanced prostate cancer can be a valuable component of support that the navigator can offer these patients and their families. Germline testing has become more readily available for people with prostate cancer, potentially impacting the health and well-being of the patient's entire family. Somatic testing can further aid in treatment decision-making for these patients, with respect to post-surgical radiation, along with targeted and systemic therapies. Navigators are tasked with the responsibility of knowing which local genetics professionals are available to service their patients. Recognizing when genetic or genomic testing is appropriate allows navigators to promptly connect patients to these current and emerging technologies.

References: 1. American Society of Clinical Oncology. The genetics of cancer. November 2019. www.cancer.net/navigating-cancer-care/cancer-basics/genetics/genetics-cancer. Accessed November 11, 2019. 2. Color 2019 website. Can cancer be inherited? www.color.com/learn/can-cancer-be-inherited-learn-about-hereditary-cancer. Accessed November 11, 2019. 3. Cheng HH, Sokolova AO, Schaeffer EM, et al. Germline and somatic mutations in prostate cancer for the clinician. *J Natl Compr Canc Netw*. 2019;17:515-521. 4. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) for Genetic/Familial High-Risk Assessment: Breast and Ovarian V.3.2019. Accessed November 11, 2019. To view the most recent and complete version of the guideline, go online to NCCN.org. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way. 5. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) for Prostate Cancer. V.4.2019. Accessed November 11, 2019. To view the most recent and complete version of the guideline, go online to NCCN.org. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way. 6. American Society of Clinical Oncology. Prostate cancer: risk factors and prevention. March 2018. www.cancer.net/cancer-types/prostate-cancer/risk-factors-and-prevention. Accessed November 11, 2019. 7. Robinson D, Van Allen EM, Wu Y-M, et al. Integrative clinical genomics of advanced prostate cancer. *Cell*. 2015;161:1215-1228. 8. Rimar KJ, Tran PT, Matulewicz RS, et al. The emerging role of homologous recombination repair and PARP inhibitors in genitourinary malignancies. *Cancer*. 2017;123:1912-1924. 9. Chung J, Dewal N, Sokol E, et al. Prospective comprehensive genomic profiling of primary and metastatic prostate tumors. *JCO Precis Oncol*. 2019;3. Epub ahead of print. Accessed November 11, 2019.

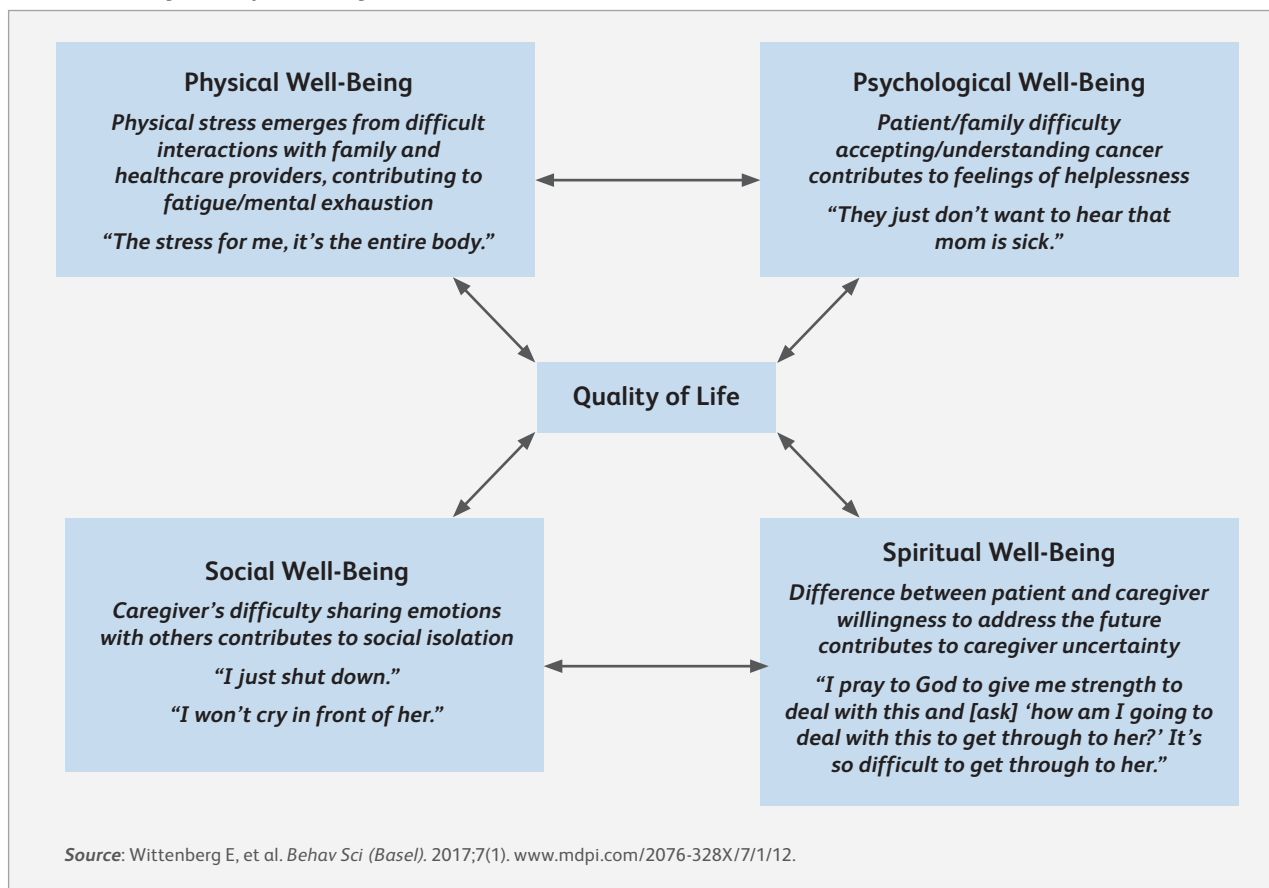
XI. PALLIATIVE CARE

Palliative care can be used at any stage of illness, but it is most often associated with advanced cancer. The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹ Specific to cancer care, patient and caregiver quality-of-life concerns should be addressed throughout the care trajectory, ideally with foundations in the City of Hope Quality of Life Model, as illustrated in **Figure 1**.² The model includes 4 domains—physical, psychological, social, and spiritual—that are essential for assessment to guarantee comprehensive, holistic quality care.² In alignment with this model, the Oncology Nursing Society’s Position Statement on Palliative Care for People with Cancer outlines key components in the optimal delivery of palliative care, as shown in **Figure 2**.³ Navigators can play a key role in this regard, educating patients about the true meaning of palliative care and facilitating referrals to the appropriate palliative care specialists in their healthcare systems.

Goals of Palliative Care

In connection with the overarching goals of palliative care, best practices promote the ongoing assessment of certain aspects of cancer care, proceeding with palliative care interventions, and,

FIGURE 1. City of Hope Quality of Life Model



ultimately, reevaluating how specific acceptable outcomes are met. This cyclical process continues to best adapt the plan of care to the status of each particular patient.

Ideally, palliative care can be initiated by the primary oncology team (including physicians, nurses, social workers, and navigators, among others) and then supplemented by collaboration with an interprofessional team of palliative care experts, to handle intractable symptoms or complex psychosocial issues. Palliative care should be viewed as quality-of-life preservation or quality-of-life restoration. All too often palliative care is discussed only when patients are too ill to receive additional treatment and hospice care is being recommended. Therefore, engaging a palliative care provider as part of the multidisciplinary team early on will help to provide patients with the best possible outcomes.

Edmonton Symptom Assessment System

To help evaluate patients for referral to palliative care, the Edmonton Symptom Assessment System (ESAS) is a validated tool used for symptom screening and monitoring in many healthcare settings, including oncology and palliative care (Figure 3).^{4,5} This simple tool can be administered easily by navigators to patients at their periodic encounters with both navigators and clinicians, encouraging frequent and ongoing

FIGURE 2. Oncology Nursing Society’s Position Statement on Palliative Care for People with Cancer: Bullet Points


It is the position of the Oncology Nursing Society (ONS) that

- All patients with cancer benefit from palliative care.
- Palliative care should begin at the time of diagnosis and continue throughout bereavement.
- Physical, psychological, social, cultural, and spiritual assessments are key components to the development of a comprehensive care plan for each patient.
- The family is the unit of care, with the patient being viewed as part of the family and family being defined by the patient.
- Palliative care is provided by an interprofessional team that includes at least physicians, nurses, social workers, and spiritual care professionals. Additional team members may include pharmacists; nursing aides; respiratory, occupational, and physical therapists; psychologists; psychiatrists; bioethicists; volunteers; and allied personnel who are skilled, credentialed, or certified in the essentials of palliative care.
- The interprofessional team must recognize the complexity of the patient and family experience and be prepared to adjust care and goals based on the patient’s or family’s expressed needs.
- Family conferences to address goals of care are essential to ensure that the team continues to remain focused on the patient’s needs and goals of care.
- Oncology nurses are in a unique position to advocate for patients regarding access to and the delivery of quality palliative care.
- Oncology nurses must possess knowledge and skills in certain domains to deliver safe, quality palliative care, including (a) structure and processes of care; (b) physical aspects of care; (c) psychological and psychiatric aspects of care; (d) social aspects for care; (e) spiritual, religious, and existential aspects of care; (f) cultural aspects of care; (g) care of the person nearing the end of life; and (h) ethical and legal aspects of care (National Consensus Project, 2018).
- Systems should make advance care planning a priority to ensure that patients’ values and wishes are honored.
- Palliative care principles, at minimum, are incorporated into all oncology care sites and subspecialties, and access to palliative care experts is available for patients in all settings. Ideally, dedicated palliative care professionals are available for patients and families throughout the continuum of their illness.
- Oncology nurses have a responsibility to engage the public and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choices based on the needs and values of individuals.

Approved by the ONS Board of Directors, November 2014. Reviewed January 2015, January 2016, March 2019.

Source: Oncology Nursing Society. www.ons.org/sites/default/files/2019-05/Palliative_Care_for_People_with_Cancer_2019.pdf.

FIGURE 3. Edmonton Symptom Assessment System, Revised Version (ESAS-R)



**Edmonton Symptom Assessment System:
(revised version) (ESAS-R)**

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
<hr/>												
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
<hr/>												
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
<hr/>												
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
<hr/>												
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
<hr/>												
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
<hr/>												
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
<hr/>												
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
<hr/>												
Best Well-being <i>(Well-being = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Well-being
<hr/>												
No _____ <i>Other Problem (for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____

Date _____ Time _____

Completed by (check one):

Patient

Family caregiver

Healthcare professional caregiver

Caregiver-assisted

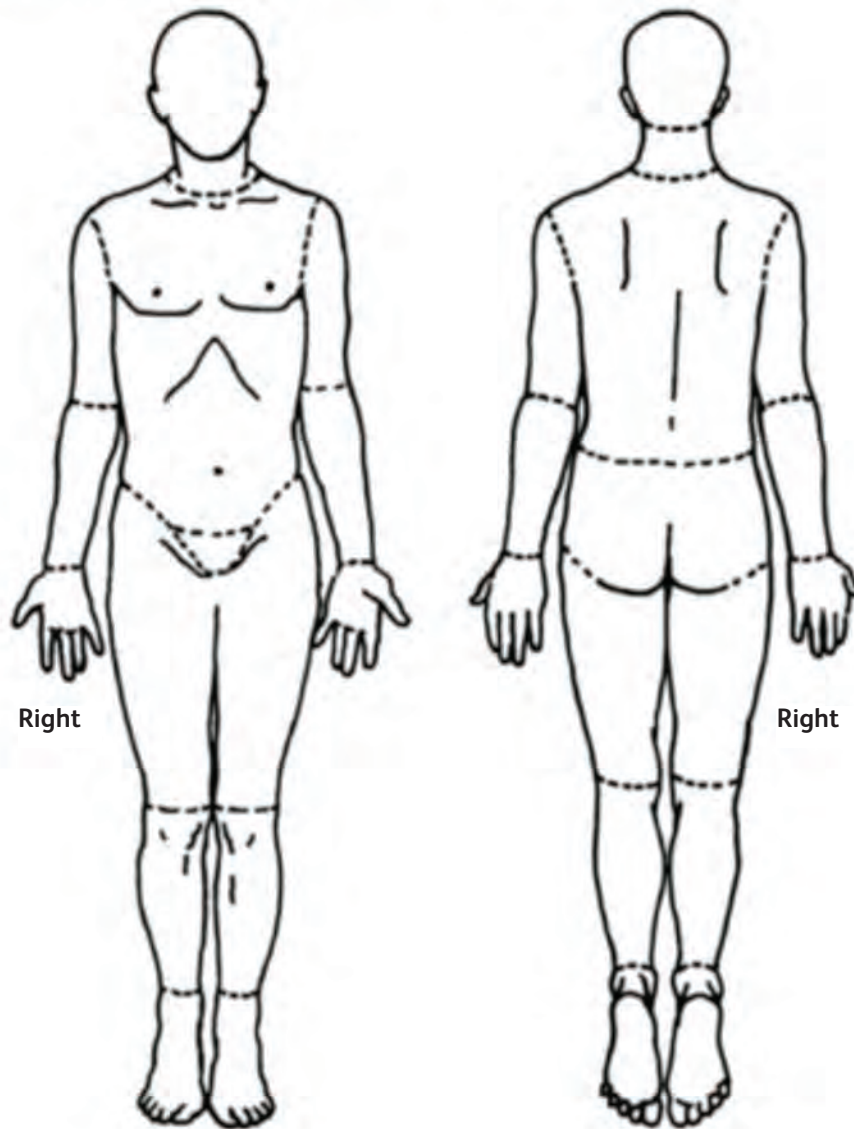
BODY DIAGRAM ON REVERSE SIDE

ESAS-r
Source: <http://www.palliative.org/NewPC/professionals/tools/esas.html>.

(continued)

FIGURE 3. Edmonton Symptom Assessment System, Revised Version (ESAS-R) (continued)

Please mark on these pictures where it is that you hurt:



Sources: Hui D, Bruera E. *J Pain Symptom Manage.* 2017;53:630-643; Alberta Health Services. Palliative & end of life care (PEOLC): information for health professionals. 2019. www.palliative.org/NewPC/professionals/tools/esas.html.

assessments to promptly identify when referral to palliative care can best serve the patient with advanced prostate cancer.

Roles and Responsibilities of the Palliative Care Team

Although the primary oncology care team, in collaboration with navigators, can address many issues relevant to palliative care, there is a point at which referral to a palliative care specialist may be required. The ESAS can be an excellent screening tool for the identification of appropriate referrals to palliative care. A specialty palliative care department integrates palliative care providers and interdisciplinary palliative care teams, including board-certified palliative care physicians, advanced practice nurses, physician assistants, social workers, chaplains, and pharmacists. These individuals should be available to provide consultative or direct care to patients/families/caregivers or healthcare professionals who request or require their expertise.

The Navigator's Role in Palliative Care

With an understanding of the goals and objectives of palliative care, navigators can educate patients and their families about these concepts, reducing any misconceptions so that they are more comfortable when being referred to specialty palliative care services, when needed. Palliative care is commonly confused with hospice and end-of-life care, so it is important to convey to patients that palliative care is not terminal illness care, but rather chronic illness care, and that it is appropriate at any age and at any stage of disease.⁶

In palliative care, distinctions exist between a clinical navigator's role and a nonclinically licensed navigator's role. Clinical navigators can conduct thorough, multifaceted assessments and interventions, including the use of the ESAS tool to evaluate patients for a palliative care referral, along with distress assessment, patient/family education, and multidisciplinary team communication and assistance with care transitions.

With an understanding of the role played by palliative care in patients with advanced prostate cancer, nonclinically licensed navigators can observe and then report to the oncology nurse navigator and the oncology care team when the patient is experiencing concerns or issues that require further assessment, evaluation, and intervention. They can then assist with logistics and scheduling needs that are specific to palliative care.

Case Study on Palliative Care with Mr Aquino—A Patient Diagnosed with Advanced Prostate Cancer

The following case study was adapted originally from Stanford University School of Medicine's module on palliative care, "Case Study: Mr Aquino,"⁷ and was modified to show the impact of navigation on palliative and end-of-life care.

Initial Diagnosis

Carlos Aquino, a 63-year-old Filipino male with metastatic castration-resistant prostate cancer, is in the clinic today to check in with the advanced prostate cancer navigator. Mr Aquino was diagnosed with benign prostatic hypertrophy several years ago and was being treated with alpha blockers for this condition.

Approximately 1 year ago, his symptoms of benign prostatic hypertrophy worsened despite maximal therapy. At that time, Mr Aquino's physician performed a digital rectal examination and noted that the patient had a new hard nodule (1 cm × 1 cm) in the right lobe of his prostate and a prostate-specific antigen (PSA) level of 2.4 (his PSA level in the previous year had been 2.2). A prostate biopsy revealed high-grade adenocarcinoma in 5 of 5 right lobe biopsy specimens, with a Gleason score of 4+5, and in 2 of

5 left lobe biopsy specimens. A bone scan detected a small focal abnormality in the lumbar spine at the level of the L2 vertebra. The patient's prostate cancer was staged as T2b.

Medical History

- Severe gastroesophageal reflux disease
- Coronary artery disease status post-myocardial infarction 2 years ago, with a history of left circumflex percutaneous transluminal coronary angioplasty
- Pulmonary nodules 2 mm, stable per computed tomography for the past 5 years
- Hypertension
- History of depression
- Current tobacco abuse
- Hyperlipidemia.

When a new diagnosis of advanced prostate cancer has been rendered, the plan of care for patients with nodal or metastatic disease has a set of goals different from the treatment plan for those with clinically localized disease.

Social History

The patient was born and raised in Manila, the Philippines. He completed high school and then worked in the Philippines. A few years ago, he immigrated to the United States, having been sponsored by his sister, who lives in the country. He has been married to his wife for 35 years and has 3 adult children.

Advanced Prostate Cancer Navigator Interventions: Pretreatment

When a new diagnosis of advanced prostate cancer has been rendered, the plan of care for patients with nodal or metastatic disease has a set of goals different from the treatment plan for those with clinically localized disease. At this phase of care, the advanced prostate cancer navigator may consider the following interventions:

- Interview the patient and caregiver to elucidate their understanding of the stage and grade of the disease and their perceived goals of treatment, and to learn more about the patient's personal life (ie, marriage status, children, greatest concerns or fears, hopes, assessment of possible treatment barriers)
- Administer the ESAS tool to generate patients' and caregivers' thoughts about palliative care; refer for palliative care evaluation, as appropriate. Patients with multiple comorbidities, such as Mr Aquino, may consider palliative care because of factors beyond the realm of cancer
- Administer the National Comprehensive Cancer Network Distress Thermometer⁸ to identify needs in all domains based on the Quality of Care Model
- Offer referral to a social worker for additional mental, emotional, social, and practical support.

At Time of Diagnosis

The patient was seen by the medical oncology team and then by the radiation oncology team. Their recommendation was for Mr Aquino to undergo radiation treatment (external beam intensity-modulated radiation therapy), followed by hormonal therapy and a possible trial of docetaxel. The ESAS tool revealed several areas of concern (with the patient having rated his pain and anxiety at a level of 7). The Distress Thermometer revealed an overall level of 5 (of a possible 10), with most of the patient's concerns focused on family matters (Mr Aquino's 2 sons are graduating from college in 1 year, and he is the main source of financial support for them). In Mr Aquino's discussion with the advanced prostate cancer navigator, it was agreed that referrals to palliative care and social work may be helpful.

Advanced Prostate Cancer Navigator Interventions: Treatment Decision-Making

The next phase of care focuses on treatment decision-making. The advanced prostate cancer nurse navigator may need to assist the patient by supporting clinical decision-making based on known findings or help reinforce the patient's understanding of the expected course of care, along with anticipated side effects and their management. Side effects can occur beyond the physical domain and can arise in any of the 4 domains of the Quality of Care Model—that is, physical, psychological, social, and spiritual. At this phase of care, the nurse navigator may consider the following interventions:

- Assist with treatment decision-making, using shared decision-making tools in alignment with the SHARE (Seek, Help, Assess, Reach, Evaluate) model (*refer to Section III in this toolkit*), particularly with respect to the multiple choices offered to the patient in terms of hormonal therapy, as well as the consideration of chemotherapy
- Interview the patient to gain his understanding of the stage and grade of his disease, as well as his perceived goals regarding the various available treatment options
- Assess the patient's treatment goals once again with respect to all 4 domains of the Quality of Care Model, addressing Mr Aquino's specific concerns regarding family and financial issues. Provide follow-up counseling to ensure that the patient's goals are realistic, given the clinical status of his advanced prostate cancer.

At 6-Month Post-Cancer Diagnosis

Mr Aquino received external beam intensity-modulated radiation therapy directed at the prostate and pelvic lymph nodes, and he was placed on hormonal therapy and a trial of docetaxel chemotherapy. Upon

The advanced prostate cancer nurse navigator may need to assist the patient by supporting clinical decision-making based on known findings or help reinforce the patient's understanding of the expected course of care, along with anticipated side effects and their management.

the patient's complaint of increasing low back pain, a magnetic resonance imaging scan revealed bony metastases to the second and third lumbar spine vertebrae (L2 and L3). His PSA level increased to 18.6. Mr Aquino received radiation therapy directed at the spine. The advanced prostate cancer navigator recommended a palliative care consultation, and the patient and family members agreed.

At 9-Month Post-Cancer Diagnosis

Mr Aquino complained of escalating back, flank, rib, and leg pain. A second course of docetaxel was initiated. Later that month, a bone scan revealed increased uptake throughout his skull, ribs, and thoracic and lumbar spine, as well as a slightly increased uptake in the proximal left femur. His PSA level had risen to 48.4. Per palliative care, Mr Aquino's pain was initially managed with hydromorphone patient-controlled analgesia, and he is currently receiving methadone 80 mg every 8 hours.

Today (11-Month Post-Cancer Diagnosis)

The patient is here today with his sister to see the advanced prostate cancer navigator after his routine follow-up with the medical oncology team. He reports moderate control of his pain on his current pain regimen. He also states that his appetite is poor and that he is easily fatigued. He is independent with respect to his activities of daily living and instrumental activities of daily living, and even works

occasionally on those days that he feels well enough to do so. The navigator notes that Mr Aquino has lost 2 pounds since his last clinic visit 2 months ago, with his body mass index now reported to be 25.6. He is alert and oriented. His recent laboratory reports show a PSA of 70.7. The patient appears to be anxious and asks, “How much time do I have?”

Advanced Prostate Cancer Navigator Interventions: Progression

At this point in Mr Aquino’s care, the progression of disease is inherent. His clinical indicators are worsening, and he exhibits anxiety related to his own prognosis. The navigator should begin by ensuring that the patient promptly meets again with the palliative care team to reassess his goals of care and treatment expectations. This is also the time to prepare for a care transition from palliative care to end-of-life care. At this phase of care, the nurse navigator may consider the following interventions:

- Assess the patient’s and the caregiver’s understanding of metastatic castration-resistant prostate cancer, and redefine Mr Aquino’s goals of care at this point
- Inquire as to whether the patient and caregiver continue to benefit from working with the palliative care and social work teams; collaborate and consult with healthcare colleagues to ensure that the current plan of care is in accordance with the patient’s needs and goals
- Reinforce education on the differences between palliative care and end-of-life care; encourage formal consultations or follow-up with palliative care and social work. Consider referral for an educational visit with hospice/end-of-life care services if the patient is amenable
- Interview the patient about his life goals to date and how these objectives might be fulfilled in alternative ways, if necessary (eg, cards for grandchildren’s milestones that will be achieved in the far distant future).

References: 1. World Health Organization. WHO definition of palliative care. 2019. www.who.int/cancer/palliative/definition/en/. Accessed November 11, 2019. 2. Wittenberg E, Borneman T, Koczywas M, et al. Cancer communication and family caregiver quality of life. *Behav Sci (Basel)*. 2017;7:E12. 3. Oncology Nursing Society. Palliative care for people with cancer. Reviewed March 2019. www.ons.org/make-difference/ons-center-advocacy-and-health-policy/position-statements/palliative-care-people. Accessed November 12, 2019. 4. Hui D, Bruera E. The Edmonton Symptom Assessment System 25 years later: past, present, and future developments. *J Pain Symptom Manage*. 2017;53:630-643. 5. Alberta Health Services. Palliative & end of life care (PEOLC): information for health professionals. 2019. www.palliative.org/NewPC/professionals/tools/esas.html. Accessed November 12, 2019. 6. Meier DE, Morgan LD. Reframing palliative care: messages matter. April 12, 2017. https://media.ccapc.org/recorded-webinars/slides/4583_2128_reframing_palliative_care_slides.pdf. Accessed November 12, 2019. 7. Periyakoil VJ. Case study: Mr. Aquino. February 19, 2016. <https://palliative.stanford.edu/prognostication/case-study-mr-aquino/>. Accessed November 12, 2019. 8. National Comprehensive Cancer Network (NCCN). NCCN distress thermometer and problem list. February 23, 2018. www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf. Accessed November 13, 2019.

XII. END-OF-LIFE CARE

End-of-life care is often confused with palliative care. Within the domains of the cancer care continuum (see *General Navigation Toolkit, Section X, p. 31, Figure 2, “Domains of the Cancer Care Continuum with Examples of Activities in Each Domain”*), although end-of-life care is the last domain in the spectrum, transitioning from palliative care to end-of-life care can be a very intense process. In this regard, navigators can have a beneficial impact on the quality of life of patients with advanced prostate cancer and their families during an extremely stressful time. Referral to palliative care can be appropriate as early as at the time of initial diagnosis and while curative anticancer treatments are being pursued. End-of-life care, in contrast, is applicable only when the patient has a prognosis of ≤ 6 months to live and has discontinued all anticancer treatment regimens. Here, we will aptly consider end-of-life care to be synonymous with hospice care. (See *Figure 1 in Section XI of this toolkit for a graphic representation of the different phases of palliative and end-of-life care.*) Navigators who assist patients with advanced prostate cancer may facilitate their care transitions through palliative and into end-of-life care. Comprehending end-of-life care, particularly in comparison to palliative care, enables navigators to best prepare patients and their families to utilize this type of care whenever necessary.

End-of-life care uses a specialty team–based approach, usually including a palliative care physician, a nurse who specializes in end-of-life care, and a social worker as the core group. Additionally, under the hospice benefit, other specific services may be utilized, as deemed necessary and requested by the core team. Those services that are usually covered include the following:

- Physician services (patients can elect 1 primary care physician as their hospice provider)
- Nursing care
- Medical equipment and supplies related to the patient’s terminal illness
- Medications for the management of pain, symptoms, and comfort
- Hospice aide services
- Physical and occupational therapy
- Social work services
- Dietary counseling
- Spiritual counseling
- Bereavement care.

End-of-life care uses a specialty team–based approach, usually including a palliative care physician, a nurse who specializes in end-of-life care, and a social worker as the core group.

A requirement of hospice care coverage is that no further curative life-sustaining cancer treatments are allowed, such as the following:

- Inpatient hospitalizations for life-sustaining treatments
- Diagnostic interventions (x-rays, laboratory work, computed tomography scans)
- Emergency department visits
- Specialist provider visits
- Outpatient services
- Ambulance services.

To qualify for this level of end-of-life/hospice care, a physician must certify the ≤ 6 -month prognosis, which requires at least 1 face-to-face visit in each of the initial two 90-day periods. For those patients who survive for longer than 6 months, recertification is needed once every 60 days, also via a face-to-face visit. Occasionally, patients unexpectedly recover to the point that they no longer require hospice

services and can resume their prior medical care. In contrast, patients often qualify for hospice care before a referral has been made. Barriers here may include physicians' overestimation of prognosis, along with a deficit in readiness on the part of patients and their families to accept hospice services. Navigators are able to have frank, honest discussions about end-of-life care, thus supporting patients with advanced prostate cancer and their families. *(See also General Navigation Toolkit, Section XI, p. 41-43, "Case Scenario: Navigating the Continuum of Care.")*

Goals of End-of-Life Care

The overarching goal of end-of-life care is to optimize quality of life for individuals who are in the final phases of a disease that cannot be cured. The focus is broad and aims at addressing all aspects of potential suffering, including physical symptoms, psychological and social distress, and spiritual pain; assistance with practical tasks may also be included. By decreasing, relieving, and preventing suffering through end-of-life care, patients can take care of the business in their lives and focus more of their energy on family and friends.¹

Relief of pain is usually a patient's first thought when considering his or her physical comfort. Discomfort also can arise from mental and emotional distress. Patients who are receiving end-of-life care have specific worries and concerns, including fear of the unknown; worrying about those left behind; fear of being alone at the end of their life; and/or concerns about how their family and friends are reacting (eg, not knowing what to say or early grieving and/or withdrawal). Spiritual needs at the end of one's life may carry nearly as much weight as do physical and emotional needs, including finding meaning in one's life; resolving unsettled issues with loved ones; and/or struggling with faith. In support of the patient and the caregiver, although practical needs can be simply addressed, they can have a major impact on quality of life. Assuming small daily chores around the house, such as getting the mail, doing a load of laundry, feeding pets, taking children to sports practice, or picking up medicine from the pharmacy, can provide a much-needed break for caregivers. Keeping close friends and family informed can feel overwhelming for patients and their families. For additional practical support, one can set up an outgoing voicemail message, an e-mail list, a private Facebook page, or even a phone tree; some families create a blog or a website to share their news, thoughts, and wishes.

Optimal end-of-life care extends beyond the death of the patient, providing continuing support for the family. The National Comprehensive Cancer Network (NCCN) Guidelines include a death as an expected outcome and after-death care for the family as an essential part of the continuum of cancer care. The definition of a "peaceful death," per the NCCN Palliative Care Panel, is characterized as being one that is²:

- Free from avoidable distress and suffering for the patient, the family, and the caregiver(s)
- In general accord with the patient's and the family's wishes
- Consistent with clinical, cultural, and ethical standards.

Specific elements are involved in the patient experiencing a good, peaceful death. These components must be discussed when a patient has likely reached the point of time in which he or she has ≤ 6 months to live. These elements include the following³:

- Knowing that you had purpose for living and that it was valued by at least 1 other person

Specific elements are involved in the patient experiencing a good, peaceful death. These components must be discussed when a patient has likely reached the point of time in which he or she has ≤ 6 months to live.

- Leaving a legacy that is unrelated to leaving money
- Having all of your financial and legal affairs in order
- Leaving no financial debt for the family to pay that is associated with the patient's cancer care
- Giving forgiveness and receiving forgiveness
- Being pain-free
- Dying with dignity in the environment of your choosing
- Feeling confident that you will be spoken of fondly after you are gone
- Feeling connected spiritually to a higher power.

Patients need resources to accomplish many of these things. Simply telling a patient to get his or her affairs in order accomplishes nothing. Patients need readily available resources to achieve these things, such as having their financial and legal affairs in order.

After-death interventions in end-of-life care are focused on the family/caregivers but also on healthcare professionals. Family/caregivers should receive immediate after-death care, including interventions such as the following:

- Informing family (if not present) of the patient's death
- Offering condolences
- Ensuring culturally sensitive, respectful treatment of the body
- Addressing survivor concerns about organ donation and/or autopsy.

Furthermore, for family/caregivers, bereavement support can emerge through interventions that include the following:

- Formally expressing condolences on the patient's death (eg, card, call, letter)
- Referring to appropriate bereavement services within the institution or the community
- Attending a debriefing meeting with the family if they desire one.

Roles and Responsibilities of the Care Team

In sync with the goals of end-of-life care listed above, the responsibilities of the care team are focused on the physical, mental/emotional, spiritual, and practical needs of the patient and his or her family during the final phase of life and into bereavement. In the transition from palliative to end-of-life care, the roles of the care team are redistributed, with more involvement from the specialty palliative care team compared with the primary oncology team (which includes the navigator, the primary care physician, the oncologist, the oncology nurses, and the social workers). The specialty palliative care team comprises a similar interdisciplinary group, yet with more expertise with respect to carrying out those tasks that are specific to end-of-life/hospice care. Referral to a dedicated

The roles and responsibilities of the care team are very dynamic, adapting to the patient's fluctuating condition and his or her needs in end-of-life care.

hospice care service may be available in some healthcare systems. The roles and responsibilities of the care team are very dynamic, adapting to the patient's fluctuating condition and his or her needs in end-of-life care. Continued involvement of the entire spectrum of care providers, from primary care and oncology, to specialty palliative care and hospice services, is essential to fostering quality of life during this phase.

The Navigator's Role in End-of-Life Care

Nurse navigators who serve patients with advanced prostate cancer and their families provide an ongoing, stalwart role in ensuring smooth care transition into the final phases of life and into bereavement. As the patient with advanced prostate cancer progresses through the end-of-life stages, the nurse navigator intervenes with varying levels of education, support, and advocacy based on the patient's life expectancy. Reviewing the elements of experiencing a good and peaceful death should take place at frequent intervals, in order to help ensure that each of the components has been effectively achieved.

Navigators in the advanced prostate cancer arena can contribute greatly toward optimal end-of-life care, being best positioned to inform patients about the expected trajectory of care, from active anticancer treatments, through supportive palliative care servicing, and into end-of-life/hospice-level care. Navigators can also support families following the patient's peaceful death, in their transition to bereavement care. As patient acuity increases during this phase of care, multiple providers and specialties become actively involved, so navigators can contribute further by ensuring collaborative and communicative interaction among the various members of the healthcare team.

References: 1. National Comprehensive Cancer Network. Patient and caregiver resources. Understanding hospice care. www.nccn.org/patients/resources/life_with_cancer/hospice.aspx. Accessed November 13, 2019. 2. NCCN Clinical Practice Guidelines in Oncology: (NCCN Guidelines®). Palliative Care V.2.2019. Accessed November 13, 2019. To view the most recent and complete version of the guideline, go online to NCCN.org. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way. 3. Shockney LD. *Fulfilling Hope: Supporting the Needs of Patients with Advanced Cancers*. New York, NY: Nova Science Publishing; 2014.

XIII. DEVELOPING AN ADVANCED PROSTATE CANCER NAVIGATION PROGRAM

An advanced prostate cancer navigation program is often built on another generalized or disease-specific navigation program that is already in place. A community needs assessment may have revealed barriers to care that can best be addressed via use of a navigation program focused on patients with advanced prostate cancer. With most of the key components already established in a generalized multidisease or localized prostate cancer navigation program, the addition of an advanced prostate cancer navigation program can be initiated relatively quickly, and thus can better serve the needs, priorities, and resource identification specific to the advanced prostate cancer patient population. Initial development of the program should include key stakeholders in the advanced prostate cancer setting; focus groups involving patients, families, and community representatives; and any shared experience from colleagues in different care systems who have already created and maintain a similar navigation program for other advanced diseases. (See *General Navigation Toolkit, Section XII, p. 45.*)

Role Delineation

When a new oncology navigation program is being created, the core planning group commonly includes a physician, an administrator, and an oncology nurse—all of whom, ideally, have some experience in navigation. Patient navigators, social workers, and other individuals from other support services follow soon after, as program development continues. As illustrated in **Figure 1** from the Academy of Oncology

FIGURE 1. Patient-Centered Multidisciplinary Cancer Care Team in Advanced Prostate Cancer



Nurse & Patient Navigators (AONN+) Team-Based Oncology Navigation, the multidisciplinary cancer care team comprises many potential members.¹ Depending on the goals and needs of the advanced prostate cancer patient population, different members of the team can serve as the expert at various points along the care continuum, with the oncology nurse navigator/oncology patient navigator facilitating collaborations with each team member, as needed. Prior to launching an advanced prostate cancer navigation program, all roles should be clearly delineated, so that the appropriate tasks can be distributed and delegated among the members of the program when it becomes fully built. With use of the foundations established by the Oncology Nurse Navigator Competencies, which were updated most recently in 2017, role delineation can help to build job descriptions for the core roles of the advanced prostate cancer navigation program, beginning with the clinical oncology nurse navigator. The categories for both oncology nurse navigator and oncology patient navigator competencies include the following²:

- Coordination of care
- Communication
- Education
- Professional role
- Expert oncology nurse navigator/oncology patient navigator practice.

The AONN+ knowledge domains, which are depicted in **Table 1**,³ provide a framework for developing metrics to best evaluate outcomes measures as a result of oncology navigation, which can be critical in further defining and adapting roles during program development and maintenance.

More specific to nonclinical patient navigators, The George Washington University Cancer Institute published Core Competencies for Non-Clinically Licensed Patient Navigators, which cover 8 domains for patient navigation stakeholders⁴:

- Patient care
- Knowledge for practice
- Practice-based learning and improvement
- Interpersonal and communication skills
- Professionalism
- Systems-based practice
- Interprofessional collaboration
- Personal and professional development.

TABLE 1. AONN+ Knowledge Domains

Community Outreach and Prevention
Coordination of Care/Care Transitions
Patient Advocacy/Patient Empowerment
Psychosocial Support Services/Assessment
Survivorship/End of Life
Professional Roles and Responsibilities
Operations Management/Organizational Development/Healthcare Economics
Research/Quality/Performance Improvement

AONN+ indicates Academy of Oncology Nurse & Patient Navigators.

Source: Strusowski T, Johnston D. *J Oncol Navig Surviv*. 2018;9:214-221.

Navigator Competencies

Selected competencies from each category are included below, as they pertain to early program development and to creating job descriptions for the nurse and the patient navigators.

Coordination of Care

- Assesses patient needs at the initial encounter and periodically throughout navigation, matching unmet needs with appropriate services and referrals to support services
- Facilitates timely scheduling of appointments, diagnostic testing, and procedures to expedite the plan of care and promote the continuity of care

- Assists patients with cancer with all issues related to treatment goals, advance directives, palliative care, and end-of-life concerns, using an ethical framework that is nonjudgmental and nondiscriminatory.

Nurse and patient navigators must possess excellent communication skills to best serve patients and families dealing with advanced prostate cancer.

Coordination of care is essential for patients with advanced prostate cancer, often requiring visits to be scheduled quickly and efficiently in multiple departments. Patient navigators may have more responsibilities with respect to logistics and administration, whereas nurse navigators may focus more on education and counseling, particularly

when dealing with palliative care and end-of-life issues. Understanding the role of navigation across the cancer care continuum can be extremely beneficial in program development, as roles and job descriptions are being formulated.

Communication

- Acts as a liaison among the patients, families, caregivers, and providers to optimize patient outcomes
- Provides psychosocial support to and facilitates appropriate referrals for patients, families, and caregivers, particularly in times of high emotional stress and anxiety
- Facilitates communication among members of the interprofessional care team to prevent fragmented or delayed care that could adversely affect patient outcomes.

Nurse and patient navigators must possess excellent communication skills to best serve patients and families dealing with advanced prostate cancer. With a customer service mentality, navigators can optimize quality of life and patient satisfaction by continuously honing their skills in this category. Communicating constructively with fellow healthcare team members within a potentially highly stressful setting, such as advanced prostate cancer, is also critical to quality care and program development.

Education

- Assesses the educational needs of patients, families, and caregivers by considering all possible barriers to care (eg, literacy, language, cultural influences, comorbidities)
- Orients and educates patients, families, and caregivers about the cancer healthcare system, the roles of the interprofessional team members, and the available resources
- Provides anticipatory guidance and manages expectations to assist patients in coping with a cancer diagnosis and its potential or expected outcomes.

Anticipating the educational needs of patients with advanced prostate cancer and their families, as well as provider preference, is an essential role that navigators can assume. Possessing a working knowledge of the complex clinical pathways expected with nodal and metastatic prostate cancers, navigators can compile advanced prostate cancer–specific educational resources that are best suited for this patient population, including considerable resources from UsTOO.org, Cancer.org, and many other organizations (see *this toolkit*, Section XV). Deciphering the medical jargon and complexities of treatment decision-making can be an arduous process without dedicated guidance; nurse and patient navigators can excel in this category. In the advanced prostate cancer arena, significant potential educational needs can be met through competent navigation.

Professional Role

- Promotes lifelong learning and evidence-based practice to improve the care of patients with a past, current, or potential diagnosis of cancer

- Contributes to the oncology nurse navigator/oncology patient navigator program and role development, implementation, and evaluation within the healthcare system and community
- Participates in the tracking and monitoring of metrics and outcomes, in collaboration with administration, to document and evaluate outcomes of the navigation program and report findings to the cancer committee.

In addition to facilitating excellent patient care, navigators must promote the profession of navigation as a whole. Patient, families, and healthcare providers should clearly recognize the value of navigation services, assisted in part by marketing and sharing outcomes data specific to metrics that benefit from navigation. In advanced prostate cancer, providers in urology, radiation oncology, and medical oncology should be made aware of the specific navigation services that are available to their patients. The oncology nurse navigator/oncology patient navigator should participate in any tumor boards or other multidisciplinary meetings in uro-oncology to best represent and advocate for the needs of patients with advanced prostate cancer and their families. Navigators should pursue lifelong learning, so as to move them from novice to expert with respect to enhancing the navigation process in advanced prostate cancer.

Expert Oncology Nurse Navigator/Oncology Patient Navigator Practice

- Assists in gap analysis, quality improvement, process improvement measures, and data analysis; makes recommendations to the cancer committee for appropriate navigation program changes related to the data
- Contributes to program growth through collaboration with the cancer program administration to develop a marketing strategy to support the navigation program
- Orients, mentors, and guides novice oncology nurse navigators and oncology patient navigators.

Expert oncology nurse navigators and patient oncology navigators often have all the tools necessary to develop programs that facilitate the cancer care navigation process. As your program grows, expert oncology nurse navigators/oncology patient navigators can mentor new team members, nurse and patient navigators, and administrative staff. Sometimes expert oncology nurse navigators/oncology patient navigators need to assume a more administrative role to move the program as a whole forward. This role may involve additional responsibilities in marketing, outcomes measures, quality control, community outreach, philanthropy, and other high-level tasks. Ideally, the program can have both an expert oncology nurse navigator and an expert oncology patient navigator, so that a team-based leadership model can best develop the advanced prostate cancer program. The expert oncology nurse navigator can emphasize clinical tasks and outcomes, whereas the expert oncology patient navigator may focus on administrative and logistical issues, as well as on marketing and community outreach. Seasoned oncology nurse navigators and oncology patient navigators should be aiming for the highest level within their scope of practice, particularly in a program that addresses the complexities of patients with advanced prostate cancer.

References: 1. Franklin EF, House L, Glidden E. Understanding role delineation of the multidisciplinary team members. In: Shockney LD, ed. *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Cham, Switzerland: Springer International Publishing AG; 2018:275-290. 2. Baileys K, McMullen L, Lubejko B, et al. Nurse navigator core competencies: an update to reflect the evolution of the role. *Clin J Oncol Nurs*. 2018;22:272-281. 3. Strusowski T, Johnston D, AONN+ evidence-based oncology navigation metrics crosswalk with national oncology standards and indicators. *J Oncol Navig Surviv*. 2018;9:214-221. 4. Pratt-Chapman ML, Willis LA, Masselink L. Core competencies for non-clinically licensed patient navigators. 2014. <https://smhs.gwu.edu/gwci/sites/gwci/files/PN%20Competencies%20Report.pdf>. Accessed November 14, 2019.

XIV. ADVANCED PROSTATE CANCER BEST PRACTICES

In the pursuit of optimal patient-centered care for individuals with advanced prostate cancer, multiple reliable resources for best practices are available, ranging from individual peer-reviewed articles in the literature to comprehensive projects disseminated by key cancer care organizations, such as the Academy of Oncology Nurse & Patient Navigators (AONN+), the Association of Community Cancer Centers, the Oncology Nursing Society, and the National Comprehensive Cancer Network. The incorporation of such a vast number of resources into the focused development of a new advanced prostate cancer navigation program can seem overwhelming. For the improved focus of efforts, standardized metrics in navigation can be utilized in program planning and development, as well as measuring outcomes, all in alignment with advanced prostate cancer best practices. As a framework, the AONN+ Standardized Evidence-Based Metrics can be used to guide the development of an advanced prostate cancer navigation program.¹ **Table 1** lists 10 standardized evidence-based metrics, along with suggested applications in advanced prostate cancer best practices.²

References: 1. Strusowski T, Johnston D. AONN + evidence-based oncology navigation metrics crosswalk with national oncology standards and indicators. *J Oncol Navig Surviv.* 2018;9:214-241. 2. Strusowski T, Sein E, Johnston D, et al. Standardized evidence-based oncology navigation metrics for all models: a powerful tool in assessing the value and impact of navigation programs. *J Oncol Navig Surviv.* 2017;8(5):220-237.

TABLE 1. Selected AONN+ Metrics and Suggested Applications to APC

Domain	Metric	APC applications toward best practices
Coordination of Care/ Care Transitions	Barriers to care; measuring the number and list of specific barriers to care identified by navigator per month	Common barriers to care (<i>see Section VII of this toolkit</i>) exists in several domains — Patient/caregiver issues — Healthcare team issues — Healthcare system issues Early APC navigator program development may consider focusing on logistical barriers first and referral patterns
Coordination of Care/ Care Transitions	Diagnosis to initial treatment; measuring the number of business days from diagnosis (date pathology resulted) to initial treatment modality (date of 1st treatment)	Diagnosis in APC would be first sign of recurrence after primary therapy if completed If primary therapy not completed, timeline would begin at first sign of advanced disease (regional or metastatic)
Operations Management/ Organizational Development/ Healthcare Economics	Navigation caseload; measuring number of new cases, open cases, and closed cases navigated per month	Besides considering amount of caseload alone, acuity measures should be helpful in determining navigation resources needed, especially in APC High-acuity patients may demand more time per individual case
Operations Management/ Organizational Development/Health Economics	Measuring the number of navigated patients readmitted to the hospital at 30, 60, and 90 days	APC patients have multiple, sometimes concurrent, treatment modalities that increase risk for hospital admission
Psychosocial Support Services/Assessment	Psychosocial distress screening; measuring the number of navigated patients per month who received psychosocial distress screening at a pivotal medical visit using the NCCN Distress Thermometer tool	With APC patients seeing multiple providers, explore possibility of administering the NCCN Distress Thermometer tool across departments, so patients can be assessed frequently Electronic medical record may be an efficient way to collect and share Distress Thermometer results among the healthcare team

(continued)

TABLE 1. Selected AONN+ Metrics and Suggested Applications to APC (*continued*)

Domain	Metric	APC applications toward best practices
Psychosocial Support Services/Assessment	Social support referrals; measuring number of navigated patients referred to support network per month	Although multiple support resources may be available in APC, consider focusing on one service at a time for analysis (eg, social work, mental health counselors, or community support groups), during the program development phase Initially, quality assessment and process improvement interventions can be conducted on a small scale with quick turnaround
Survivorship/End of Life	Palliative care referral; measure number of navigated patients referred for palliative care per month	All APC patients should be referred to palliative care as early as possible Consider measuring total number of APC patients, along with relative numbers for: — Patients referred and palliative care service started — Patients referred, but palliative care service not taken (deferred by patient vs caregiver vs provider)
Patient Advocacy/Patient Empowerment	Identify learning style preference; measuring the number of navigated patients per month whose preferred learning style was discussed during the intake process	In the absence of a valid, established tool, consider including the following on an intake form or initial interview: — Visual (spatial): You prefer using pictures, images, and spatial understanding — Aural (auditory-musical): You prefer using sound and music — Verbal (linguistic): You prefer using words, both in speech and writing — Physical (kinesthetic): You prefer using your body, hands, and sense of touch — Logical (mathematical): You prefer using logic, reasoning, and systems — Social (interpersonal): You prefer to learn in groups or with other people — Solitary (intrapersonal): You prefer to work alone and use self-study
Professional Roles and Responsibilities	Navigation knowledge at time of orientation; measuring percentage of new hires who have completed institutionally developed navigator core competencies	Once program development has been completed for the most part, the new APC nurse and/or patient navigator should be evaluated by an expert ONN or physician champion, to assess practical competency (ensure that they are ready to begin practice as novice APC navigators) Mentors should be identified to encourage steady development into expert APC ONN practice
Research/Quality/Performance Improvement	Patient experience/patient satisfaction with care; measuring patient experience or patient satisfaction survey results per month	Consider a brief patient satisfaction survey that is in alignment with program-specific goals Focus groups that include men with APC and their families may be useful to gather feedback once an ample number of cases in navigation have been initiated

AONN+ indicates Academy of Oncology Nurse and Patient Navigators; APC, advanced prostate cancer; NCCN, National Comprehensive Cancer Network; ONN, oncology nurse navigator.

Source: Adapted from Strusowski T, Sein E, Johnston D, et al. Standardized evidence-based oncology navigation metrics for all models: a powerful tool in assessing the value and impact of navigation programs. *J Oncol Navig Surviv.* 2017;8(5):220-237.

XV. RESOURCES FOR ADVANCED PROSTATE CANCER

Links to all outside sites are provided as a resource. Pfizer accepts no responsibility for the content of the sites that are not owned and operated by Pfizer.

General Information

(See the General Toolkit, Section XVIII, for additional resources.)

Agency for Healthcare Research and Quality (AHRQ): The SHARE Approach to Clinical Decision Making
www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html

American Cancer Society: Prostate Cancer
www.cancer.org/cancer/prostate-cancer

American Joint Committee on Cancer (AJCC): Quick Reference Posters, Including Prostate
<https://cancerstaging.org/references-tools/quickreferences/pages/default.aspx>

American Society of Clinical Oncology (ASCO): Cancer.Net: The Genetics of Cancer
www.cancer.net/navigating-cancer-care/cancer-basics/genetics/genetics-cancer

American Society of Therapeutic Radiation and Oncology (ASTRO): RTAnswers.org
<https://rtanswers.org/cancer-types/prostate-cancer>

American Urological Association Urology Care Foundation: What Is Advanced Prostate Cancer?
www.urologyhealth.org/urologic-conditions/advanced-prostate-cancer

CancerCare
www.cancercare.org

Edmonton Symptom Assessment System (ESAS)
www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf

Expanded Prostate Cancer Index Composite for Clinical Practice (EPIC-CP): Quality of Life Assessment Tool for Prostate Cancer
www.bidmc.org/centers-and-departments/cancer-center/cancer-center-programs-and-services/prostate-cancer-center/prostate-cancer-faqs/epic

Facing Our Risk of Cancer Empowered (FORCE): Genetic Testing for Men with Prostate Cancer
www.facingourrisk.org/understanding-brca-and-hboc/information/hereditary-cancer/hereditary-genetics/

National Cancer Institute: Prostate Cancer
www.cancer.gov/types/prostate

National Comprehensive Cancer Network (NCCN) Guidelines for Patients: Distress
www.nccn.org/patients/guidelines/content/PDF/distress-patient.pdf

National Comprehensive Cancer Network (NCCN) Guidelines for Patients: Prostate Cancer
www.nccn.org/patients/guidelines/prostate/index.html

National Society of Genetic Counselors (NSGC): Find a Counselor
www.nsgc.org/page/find-a-genetic-counselor

Oncology Nursing Society (ONS): Oral Adherence Toolkit
www.ons.org/clinical-practice-resources/oral-adherence-toolkit

Ottawa Hospital Research Institute & University: Ottawa Personal Decision Guide
<https://decisionaid.ohri.ca/docs/das/OPDG.pdf>

Prostate Conditions Education Council (PCEC): Advanced Prostate Cancer
www.prostateconditions.org/about-prostate-conditions/prostate-cancer/advanced-disease

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Prostate Conditions Education Council (PCEC): Gleason Score

www.prostateconditions.org/about-prostate-conditions/prostate-cancer/newly-diagnosed/gleason-score

UsTOO: Principles for Managing Advanced Prostate Cancer

<https://ustoo.org/PDFs/principlesbrochure.pdf>

Advocacy Groups

American Urological Association Urology Care Foundation

www.urologyhealth.org

Cancer Support Community

www.cancersupportcommunity.org/prostate-cancer

Prostate Cancer Foundation

www.pcf.org/

Prostate Conditions Education Council (PCEC)

www.prostateconditions.org

Prostate Health Education Network

www.prostatehealthed.org

UsTOO: Prostate Cancer Treatment Options

www.ustoo.org/treatment-options#advancedprostatecancer

ZERO: The End of Prostate Cancer

www.zerocancer.org

Nutrition/Bone Health

American Cancer Society (ACS): Nutrition for People With Cancer

www.cancer.org/treatment/survivorship-during-and-after-treatment/staying-active/nutrition.html

National Cancer Institute: Prostate Cancer, Nutrition, and Dietary Supplements (PDQ®)**Patient Version**

www.cancer.gov/about-cancer/treatment/cam/patient/prostate-supplements-pdq

Prostate Cancer Foundation: Health and Wellness: Living with Prostate Cancer, Diet Recommendations

www.pcf.org/guide/health-wellness-living-prostate-cancer-part-2-diet-recommendations/

UsTOO Prostate Cancer Education & Support: What You Need to Know for Better Bone Health

www.ustoo.org/PDFs/UsTOOBoneHealthbrochure%20v2011.pdf

ZERO: The End of Prostate Cancer: Bone Loss

<https://zerocancer.org/learn/current-patients/side-effects/bone-loss>

Palliative Care

National Hospice and Palliative Care Organization (NHPCO): Palliative Care FAQs

www.nhpc.org/patients-and-caregivers/about-palliative-care/palliative-care-faqs

Oncology Nursing Society (ONS): Position Statement on Palliative Care for People With Cancer, rev. 3/2019

www.ons.org/make-difference/ons-center-advocacy-and-health-policy/position-statements/palliative-care-people

World Health Organization (WHO): WHO Definition of Palliative Care

www.who.int/cancer/palliative/definition/en

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End-of-Life Care

Hospice Foundation of America (HFA)

<https://hospicefoundation.org>

National Hospice and Palliative Care Organization (NHPCO): Hospice FAQs

www.nhpc.org/hospice-care-overview/hospice-faqs

National Institutes of Health (NIH) National Institute on Aging: Providing Care and Comfort at the End of Life

www.nia.nih.gov/health/providing-comfort-end-life

ZERO: The End of Prostate Cancer: Hospice Care and the End of Life

<https://zerocancer.org/learn/current-patients/advanced-cancer/hospice-care-end-life>

Support Groups/Peer-to-Peer Support

Cancer Support Community

www.cancersupportcommunity.org

CancerCare: Support Groups

www.cancercare.org/support_groups

National Cancer Institute – choose from a list of services; select Peer/Buddy Programs

supportorgs.cancer.gov/home.aspx?lang=1

Prostate Cancer Foundation: Support Groups

www.pcf.org/patient-resources/patient-navigation/support-groups

UsTOO: Find a Support Group

www.ustoo.org/Support-Group-Near-You

UsTOO/Imerman Angels: One-on-One Support

www.ustoo.org/One-on-One-Support

ZERO: The End of Prostate: ZERO MENtor Program

<https://zerocancer.org/get-support/mentor>

Clinical Trials

American Cancer Society (ACS): Barriers to Patient Enrollment in Therapeutic Clinical Trials for Cancer

www.fightcancer.org/policy-resources/clinical-trial-barriers

American Cancer Society (ACS): The Basics of Clinical Trials

www.cancer.org/treatment/treatments-and-side-effects/clinical-trials/what-you-need-to-know/clinical-trial-basics.html

American Society of Clinical Oncology (ASCO): Cancer.Net: About Clinical Trials

www.cancer.net/research-and-advocacy/clinical-trials/about-clinical-trials

American Society of Clinical Oncology (ASCO): Insurance Coverage of Clinical Trials

www.asco.org/research-progress/clinical-trials/insurance-coverage-clinical-trials

National Cancer Institute (NCI): Clinical Trials Information for Patients and Caregivers

www.cancer.gov/about-cancer/treatment/clinical-trials

National Cancer Institute (NCI): Find NCI-Supported Trials

www.cancer.gov/about-cancer/treatment/clinical-trials/search

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National Institutes of Health (NIH): Clinical Trials Database

<https://clinicaltrials.gov>

National Institutes of Health (NIH): Talking to Your Patient About a Clinical Trial

www.nih.gov/health-information/nih-clinical-research-trials-you/talking-your-patient-about-clinical-trial

Patient Navigator Training Collaborative: Clinical Trials and Patient Navigation

www.patientnavigatortraining.org/clinical_trials/index.htm

Caregivers

American Cancer Society (ACS): Caregiver Resource Guide

www.cancer.org/treatment/caregivers/caregiver-resource-guide.html

CancerCare (1-800-813-HOPE [1-800-813-4673]): Caregiving Resources

www.cancercare.org/tagged/caregiving

Caregiver Action Network: Caregiver Help Desk (1-855-227-3640): Community Care Corps

<https://caregiveraction.org>

Family Caregiver Alliance (FCA) 1-800-445-8106

www.caregiver.org

UsTOO: A Forum for Her – Us TOO Call-In Caregiver Support Group

www.ustoo.org/aforumforher

UsTOO: A Prostate Cancer Forum for Gay Men and Their Partners – Us TOO Call-In Support Group

www.ustoo.org/forumforgaymen

Professional Development

Academy of Oncology Nurse & Patient Navigators (AONN+)

www.aonnonline.org

Association of Community Cancer Centers (ACCC)

www.accc-cancer.org

Association of Oncology Social Work (AOSW)

www.aosw.org

Oncology Nursing Society (ONS)

www.ons.org

The Alliance of Professional Health Advocates (APHA)

<https://aphadvocates.org>

GLOSSARY OF KEY TERMS

A

adenocarcinoma: A type of cancer arising from specific tissue that forms glands. Nearly all prostate cancers are adenocarcinomas.

adjuvant therapy: Treatment given after the main treatment has been administered, to reduce the risk for cancer recurrence by eliminating any remaining cancer cells. It usually refers to chemotherapy, radiation therapy, and/or androgen-deprivation therapy administered following surgery.

adrenal glands: A pair of organs located above the kidney, which synthesize a number of important hormones, including adrenaline, androgens (in men), and steroids such as cortisol.

agonist: A chemical that binds to a receptor and activates the receptor to produce a biological response. Whereas an agonist causes an action, an antagonist blocks the action of the agonist.

alternative medicine: A treatment used in place of conventional medicine.

androgen-deprivation therapy (ADT): Treatment that removes or blocks hormones, in order to destroy or slow the growth of cancer cells.

androgen receptors: The parts of a cell that bind to androgens.

androgens: The male hormones. Generally, androgens refer to testosterone and dihydrotestosterone (DHT).

antagonist: A substance that acts against and blocks an action. Antagonist is the opposite of agonist. Antagonists and agonists are key players in the chemistry of the human body and in pharmacology.

anti-androgen: A type of drug that blocks the growth-promoting influence of androgens on the prostate gland and on prostate cancer cells.

B

benign prostatic hyperplasia (BPH): Also known as prostate gland enlargement; causes uncomfortable urinary symptoms, such as blocking the flow of urine out of the bladder.

biochemical recurrence: An increase in prostate-specific antigen (PSA) level following surgery or radiation therapy that indicates prostate cancer has recurred or spread. Also referred to as a “rising PSA” following the original prostate cancer treatment.

biomarker: A measurable substance found in the blood, urine, or body tissue whose presence is indicative of some phenomenon such as disease, infection, or environmental exposure. A cancer biomarker or tumor marker refers to a substance or process that is indicative of the presence of cancer in the body.

biopsy: A procedure for obtaining samples of tissue to determine the presence or absence of disease. It can be performed with the use of a needle or as a surgical procedure.

bone-modifying drugs: Medications used to help strengthen bones, and reduce pain and fractures (bone breaks) associated with bone metastases.

bone scan: A test in which a radioactive tracer is injected into a vein. If any skeletal bones are abnormal, the tracer accumulates in the abnormal areas. A special camera that detects the emissions from the tracer is used to take pictures of the bones after the injection. The doctor can then review the image for any abnormalities in the bones.

brachytherapy: A type of radiation therapy in which small seeds of radioactive material are placed into the prostate gland; also called interstitial radiation therapy, or “seeds.”

(continued)

C

castrate: The term used to describe dramatically low levels of testosterone (generally defined as below a level of 50 ng/dl). This state is achieved through the surgical removal of the testicles or by taking medication (hormone therapy).

castration: Surgical castration involves the removal of the testicles. Chemical/medical castration refers to the use of hormone therapy to dramatically lower testosterone levels without removing the testicles, thereby stopping the normal functioning of the testicles.

castration-resistant: The term used to describe a prostate tumor that continues to grow despite low levels of male hormones (androgens), ie, a testosterone level below the threshold of 50 ng/dl.

chemotherapy: A treatment that uses drugs that stop the growth of cancer cells, either by killing the cells directly or by stopping them from dividing.

clinical trial: A research study involving volunteers that tests treatments and/or prevention methods to learn whether they are safe, effective, and possibly better than the current standard of care, which is the best-known approach.

combined androgen blockade: The use of an anti-androgen with a luteinizing hormone–releasing hormone (LHRH) agonist to block all androgen activity—not only the production of testosterone, but also its action in the prostate gland itself.

complementary medicine: Therapies used in conjunction with conventional medicine; sometimes referred to as integrative medicine.

computed tomography (CT) scan: A type of radiologic test in which organs can be visualized with the aid of x-rays and computers.

D

definitive therapy: A therapy that may be final, superior to others, curative, or all of those.

destination therapy: A therapy that is the final destination rather than a bridge to another therapy.

differentiated: A term used to describe the normal process of cell development; applied to cancer, it describes how closely the cancer resembles the organ from which it originated. The terms well-differentiated, moderately differentiated, and poorly differentiated are commonly used as a way of grading cancer.

digital rectal examination (DRE): A part of the physical examination in which the physician puts a gloved finger into the rectum, and examines the prostate gland and the rectum for abnormalities that can be detected by touch.

E

external-beam radiation therapy (EBRT): A type of radiation therapy that uses an external source (called a linear accelerator) of radiation, which is aimed at the cancer.

extracapsular: When referring to the prostate gland, the term denotes the tissue surrounding the natural boundary of the prostate gland. Extracapsular disease is cancer that has spread to this surrounding tissue.

extraprostatic: Disease that has spread beyond the prostate gland.

F

focal therapies: Less invasive treatments that destroy small prostate tumors without treating the rest of the prostate gland.

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free prostate-specific antigen (PSA): PSA that floats freely in the bloodstream, unbound to other proteins. See prostate-specific antigen (PSA).

free testosterone: Testosterone that floats freely in the bloodstream, is unbound to carrier molecules, and is readily available to cells.

G

Gleason score: A system of identifying and grading the appearance of prostate cancer, as viewed under a microscope. The most commonly used prostate cancer grading system, with scores ranging from 2 to 10. The Gleason score is based on how closely the prostate cancer cells resemble healthy tissue when viewed under a microscope. A higher score indicates a higher risk group.

gynecomastia: The abnormal growth of breast tissue by men; a possible side effect of ADT.

H

high-intensity focused ultrasound (HIFU): A type of focal therapy that uses energy from sound waves to generate heat that destroys cancer cells in the prostate, while limiting damage to the rest of the prostate gland.

hormone-refractory disease: When referring to prostate cancer, disease that is no longer sensitive to the beneficial effects of hormone therapies.

hormone therapy (for prostate cancer): Treatments (medical or surgical) intended to reduce or eliminate the supply of male hormones to the prostate and metastases, causing cell death and slowing cancer growth.

hot flashes: Sweats or a hot and flushed feeling; a side effect of hormonal therapy for prostate cancer.

I

immunotherapy: A therapy designed to boost the body's natural immune response to fight cancer, using materials made either by the body or in a laboratory.

intensity-modulated radiation therapy (IMRT): A type of radiation therapy that allows physicians to change the intensity of radiation within each of the radiation beams.

intermittent hormone therapy: Treatment for prostate cancer that alternates cycles of hormone therapy with off-treatment periods.

L

lesion: A general term indicating an abnormality; usually, one found during physical examination, or radiologic evaluation, or at surgery.

linear accelerator: A type of radiation machine that delivers high-energy radiation waves to diseased areas of the body, usually for the treatment of cancer.

local recurrence: The reappearance of a cancer in a localized area, such as the prostate gland; generally refers to an area that has previously been treated.

localized: When used alone or with the term cancer, generally refers to cancer that is limited to a specific gland, without any distant spread; an organ-confined cancer. Cancer that is confined to the area where it began and that has not spread to other parts of the body. Also called noninvasive cancer or early-stage cancer.

luteinizing hormone (LH): A hormone released from the brain that controls the production of androgens by the testes.

luteinizing hormone-releasing hormone (LHRH): A hormone released from the brain that controls the release of luteinizing hormone.

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luteinizing hormone–releasing hormone (LHRH) agonists: Drugs used to treat prostate cancer by preventing the secretion of LHRH, which stimulates testosterone production.

luteinizing hormone–releasing hormone (LHRH) analogue: A chemical hormone similar in structure to LHRH, which is used as a treatment for prostate cancer.

lymph nodes: Small, specialized clusters of tissue that help fight infection and capture cancer cells that have moved out of a given tissue or organ.

M

magnetic resonance imaging (MRI): Uses magnetic fields, not x-rays, to produce detailed images of the body and measure tumor size; when combined with transrectal ultrasound (TRUS) to better identify areas that are more likely to be cancerous and should be biopsied, it is called an MRI fusion biopsy.

metastatic: Refers to cancer that has spread throughout the body, beyond the organ or tissue in which it originated.

micrometastases: Cancer cells outside the primary tumor, such as in the lymph nodes, that are still too small to be detected by CT, by bone scan, or by physical examination.

multidisciplinary: Involving healthcare providers from different fields who combine their expertise and skills to offer care; a multidisciplinary approach to cancer treatment might involve physicians from different specialties, nurses, and social workers.

multimodality: The combination of several disciplines or specialties in managing and recommending treatment for a patient with cancer. An example includes a team that comprises a surgeon, a radiation oncologist, and a medical oncologist.

N

nadir: The lowest level; often used in reference to prostate-specific antigen (PSA).

nanograms per milliliter (ng/mL): A small quantity of a substance; equivalent to 1 one-billionth of a gram (454 grams = 1 pound) in 1 one-thousandth of a liter (1 liter = approximately 1 quart).

neoadjuvant hormonal therapy: The use of hormonal treatment of prostate cancer prior to prostatectomy or radiation therapy.

neoadjuvant therapy: Treatment administered prior to the main therapy. It may include chemotherapy, radiation therapy, or ADT administered prior to surgery, in order to shrink a tumor so that it is easier to remove.

neurovascular bundles: Bandlike structures that run alongside the prostate gland, and contain the nerves and blood vessels necessary for the maintenance of erectile function and potency.

nocturia: A condition characterized by waking from sleep with the need to urinate 1 or more times during the night.

nodal: Pertaining to the lymph nodes or contained within the lymph nodes.

nomogram: A chart or graph of mathematical calculations of risk; used in making treatment recommendations and predicting outcomes.

nuclear medicine: The specialty that involves the use of radioactive materials (radioisotopes) for the diagnosis and treatment of disease; includes bone scans.

nucleic acid: A class of organic molecules that includes DNA and RNA.

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O

observation: Monitoring or observing a patient without performing any active interventions.

oncologist: A physician who deals with the diagnosis and treatment of cancer. There are 3 types of oncologists: medical oncologists, radiation oncologists, and surgical oncologists.

orchiectomy: The surgical removal of one or both testicles, usually as a type of hormonal therapy for prostate cancer.

organ-confined: A cancer that is contained within the prostate gland without extension to the prostate capsule or beyond.

P

palliative: Treatments intended to relieve symptoms rather than effect a cure.

palliative radiation therapy: The use of radiation treatments not to cure cancer, but to alleviate cancer symptoms, such as pain.

pathologist: A physician who specializes in the interpretation of tissues and organs as viewed under a microscope. Pathologists determine the presence or absence of cancer in tissue and organ specimens.

pathology; pathologic findings: The report of any abnormalities or signs of a disease, based on direct examination (usually by a pathologist or other physician) of tissue or organs.

perineum: The area between the scrotum and the anus.

perineural invasion (PNI): Cancer that invades a nerve or a group of nerves.

placebo: A pill with no active ingredients, or a “dummy” treatment.

poorly differentiated: A term applied to the appearance of a cancer that does not resemble the organ or tissue of origin. By examining the cancer, it is difficult, if not impossible, to determine its origin.

positron emission tomography (PET) scan: Usually combined with a CT scan to create pictures of organs and tissues inside the body via use of a radioactive substance.

proctitis: The inflammation of the lower rectum; in the context of prostate cancer, it's generally the result of radiation. The main symptom is diarrhea, which often contains blood.

progression: The growth and spread of cancer, either by direct extension or metastases.

prostate-specific antigen (PSA): A substance secreted by the prostate gland, some of which passes into the bloodstream. It can be abnormally elevated in patients with prostate cancer, benign enlargement of the gland (see benign prostatic hyperplasia [BPH]), or other conditions. See PSA-based screening, PSA density, and PSA velocity.

prostatectomy: Surgical procedure for the partial or complete removal of the prostate gland.

prostatic urethra: That portion of the urethral tube that passes through the prostate gland.

PSA: See prostate-specific antigen.

PSA-based screening: Screening for prostate cancer can be done through prostate-specific antigen (PSA) screening, with or without digital rectal examination (DRE). Measuring PSA levels is done through multiple approaches, including single-threshold testing, adjusted threshold testing, velocity, and doubling time.

PSA density: The amount of PSA (as measured in the bloodstream) divided by the volume or size of the prostate gland (as measured by ultrasound examination). See prostate-specific antigen.

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PSA velocity: The rate of change in PSA over time. See prostate-specific antigen.

psychosocial effects: Emotional and social concerns related to cancer and cancer treatment that can greatly affect an individual's well-being. These may include lack of information and support; emotional difficulties, including depression and anxiety; lack of transportation; disruptions to work, school, and family life; and issues related to the cost of cancer care.

Q

quality of life: An overall sense of well-being and satisfaction with life.

R

radiation oncologist: The preferred term for radiation therapist.

radiation therapist: A physician specializing in the use of radiation to treat cancer.

radiation therapy: A treatment designed to kill cancer cells by using high-energy waves aimed directly at the cancer-containing tissue.

radiopharmaceuticals: Radioactive substances used to treat men with castration-resistant prostate cancer that has spread to the bone.

recurrence: The reappearance of cancer.

refractory (resistant): A disease is said to be refractory when it is no longer responsive or sensitive to the treatment being administered.

regimen: A treatment plan that includes which treatments and procedures will be performed, the medications and their doses, the schedule of treatments, and the duration of the treatment.

regional: When used with prostate cancer, generally refers to cancer that is no longer localized to the prostate gland; cancer spread may exist outside the organ but still be close to it.

residual disease: Cancer that is missed by treatment because it is undetected or proves to be more extensive than originally thought.

response: How the cancer reacts to the treatment; the effectiveness of a particular treatment.

restage: To reassess the anatomic areas in which a cancer is located. This is usually performed by repeating the battery of tests that determined the original stage of cancer.

S

salvage therapy: A second procedure (such as radiation therapy or surgery) used following the failure of the initial treatment to control or cure the cancer.

seminal vesicles: Structures surrounding the prostate gland that are involved in storing and screening prostate gland secretions.

side effect: An undesirable result of treatment, such as fatigue, incontinence, or erectile dysfunction.

stage of cancer: The level of advancement of cancer. The 3 general stages are localized, regional, or disseminated (metastatic). Specific stages are identified using the tumor, (lymph) nodes, and metastases, or TNM, system.

standard of care: Care that experts agree, or research shows, is the most appropriate and/or effective for a specific type or stage of cancer.

symptomatic: The presence of specific complaints resulting from a disease process.

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T

testosterone: A male hormone, or androgen, involved in the growth and development of the prostate gland and prostate cancer.

titrating: Increasing or decreasing the dosage of a medication to an effective range over a period of days or weeks.

TNM (tumor, nodes, and metastases) staging system: The most widely used cancer staging system.

total androgen blockade: The use of 2 forms of hormonal therapy (either orchiectomy and anti-androgen or LHRH analogue and anti-androgen) for the treatment of prostate cancer; also called complete androgen blockade, maximum androgen blockade, or complete hormonal therapy.

transrectal ultrasound (TRUS): A procedure in which a probe that emits high-energy sound waves is inserted into the rectum. TRUS is used to look for abnormalities in the rectum and nearby structures, including the prostate.

transurethral resection of the prostate (TURP): A treatment for BPH that removes “chips” of prostate tissue through the urethra to relieve the urinary symptoms caused by benign enlargement of the prostate gland.

U

urethra: In men, the tube that passes from the bladder through the prostate gland to the tip of the penis. It carries urine and other secretions out of the body.

urinary incontinence: The leakage of urine from the bladder.

urinary retention: The inability to urinate, usually caused by a blockage of the urinary flow.

urinary urgency: The immediate need to urinate.

W

watchful waiting: Watchful waiting involves less intensive monitoring than active surveillance. It includes periodic PSA tests, DRE tests, and/or watching for symptoms. Watchful waiting is usually recommended for older patients and for those with other serious or life-threatening illnesses.

well-differentiated: A term applied to the appearance of a cancer that resembles, to a large degree, its tissue or organ of origin.

X

x-ray: A general term used to signify the use of radiation to detect abnormalities for diagnosis, as in an x-ray test.

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