

Shared Decision-Making in Prostate Cancer Treatment

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### Abstract

This project seeks to develop a patient-centered decision-making toolkit and implement it at a local urology center to empower patients to make educated decisions about treatment choices for men newly diagnosed with localized prostate cancer. The objectives were to evaluate patient satisfaction with their treatment decision process and determine how many patients sought a second medical opinion. During the implementation of the decision-making toolkit, qualitative data from twenty-two patients were collected at three points of care. Verbal and visual responses to a set of open-ended questions were aggregated and analyzed thematically to evaluate the usefulness of the toolkit in empowering patients to be involved in the decision-making process. All patients who participated in the decision-making process using the toolkit expressed confidence with their treatment decisions and their ability to cope with side effects post-treatment. They provided positive feedback about the toolkit, their experience in the process, and decision satisfaction. In addition, no patients stated the need to seek a second medical opinion. All objectives of this project were met. The toolkit and process of care through the decision-making process were well received by patients and physicians at the urology center. Outcomes of this project led to the recommendation that the toolkit and the process of care become usual practice to support men diagnosed with prostate cancer.

*Keywords:* Shared treatment decision-making, decision-making process, prostate cancer and treatment, decision satisfaction, decision regret

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## Introduction

Current practice in prostate cancer care requires patients to decide the course of treatment within one week of diagnosis. This is a traumatic time for patients and their families, which in the absence of decision aids often leads to decreased quality of life and decision regret. The purpose of this project was to develop a patient-centered decision-making toolkit and nursing process of care to support treatment decision-making, post-treatment coping, and reduce decision regret. Upon completion, all twenty-two patients reported benefits from using the toolkit, confidence in their treatment decision, and no regrets. Being a follower of Christ enabled the author to alleviate patients' fears and to show God's love through compassionate care during a vulnerable time.

## Executive Summary

**Overview:** Prostate cancer is a leading neoplastic disease worldwide, the first and most common cancer in developed countries and the sixth most frequent cancer in developing countries. It is also the second leading cause of cancer deaths in the United States (Ilic et al., 2015). Soon after diagnosis, patients with prostate cancer face challenges in making a treatment decision based on various complex options. According to Wagland et al. (2019), clinicians take the opportunity to impose personal views regarding preferred treatment, and patients usually comply since they may not completely understand their treatment options. Wagland et al. (2019) stated, "the treatment decision-making process is challenging as there is no clear evidence to suggest one treatment is more effective than another when multiple, equally effective treatments are available and result in significant uncertainty, anxiety, and decision regret" (p. 798). To address this issue, a shared decision-making process is necessary and recommended to ensure patients receive evidence-based resources, information, and tools to participate in their treatment decision

process to improve health outcomes and reduce decision regret. According to Ilic et al. (2015), “a decision-making toolkit aims to provide people with an opportunity to make an informed decision about treatment intervention through the provision of information about the benefits, limitations, and uncertainty associated with the choice and improve a well-informed decision-making process” (p. 1304).

**Problem Statement:** The medicalized decision-making process sometimes leads to decision regret. There is no patient-centered process for treatment decision-making for men when newly diagnosed with prostate cancer. An evidence-supported solution is needed for a systems practice change and a decision-making model to be implemented in practice.

**The Vision and the Mission:** The vision for this project focused on patient empowerment to make informed cancer treatment decisions by using a nurse-led, patient-centered approach to care. This project’s mission sought to develop and implement an evidence-based treatment decision-making toolkit for patients with localized prostate cancer.

**Purpose of the Project:** This project intended to develop a shared decision-making toolkit and implement it at a local urology center to empower patients to make educated decisions about treatment choices. The toolkit and nursing practice implementations are predicated on evidence-based information about the range of treatment options, support for treatment decision-making, and a holistic approach to improve care and quality outcomes.

**Project Objectives and Outcomes:** This project focused on an evidence-based toolkit in collaboration with providers to all patients between the ages of 40-79 years to evaluate patient satisfaction. This implementation occurred at four points of care; first, at the initial diagnosis, second, with a phone call follow-up during the first week post-diagnosis, third, during an in-

person consultation at the treatment decision, and finally through an evaluation three-month post-treatment.

Another objective was to determine the number of patients who sought a second medical opinion before their treatment decisions. The short-term goals were to develop and implement a patient-centered decision-making process, and to empower patients with increased knowledge and confidence. The long-term goals were to increase patient satisfaction in their treatment choice and to improve coping behaviors post diagnosis and treatment.

**Plan/Scope of project:** This project was planned to develop and implement an evidence-based treatment decision-making toolkit for patients between 40-79 years with localized prostate cancer in a local outpatient urology clinic.

### **Problem Statement and Significance**

If patients are insufficiently involved in their care and lack evidence-based information about their disease and treatment choices, they are more likely to regret their decision and be dissatisfied with their quality of life. In the practice setting for this project, most diagnosed patients are observed to undertake their own search for information and may seek a second medical opinion before making their final decision, resulting in a delay in treatment. Many patients proceed with their provider's treatment preference. They often consult with their friends, families, and the internet during their brief period of indecision. There is no patient-centered process for localized prostate cancer treatment decision-making despite research and clinical evidence recommendations for best practice. Therefore, there is a need to develop and implement a shared decision-making toolkit to empower and support treatment decision-making in patients with localized prostate cancer. The toolkit should be implemented as part of a nurse-led, holistic

process to improve care and quality outcomes through increased patient satisfaction, confidence in decision making, and reduced decision regret.

### **Significance**

Patients are encouraged to engage in patient-centered care (Wagland et al., 2019; Rose, 2018). Physicians acknowledge the patient's preferences and provide necessary clinical information, whereas nurses provide more detailed information, support treatment decisions, and maintain continuity of care (Baker, Wellman, & Lavender, 2016). When patients cannot express their preferences and priorities, or the physician fails to provide adequate information, treatment decision-making could lead to poor coping with expected treatment outcomes, treatment decision regret, and decreased quality of life. The long-term impact on the quality of life in men with prostate cancer is determined by their process of treatment decision and choice of treatment. The level of involvement may vary between patients; therefore, the nurse must take the lead in providing best practices for prostate cancer care by imparting appropriate treatment options, prevalence data, and potential severity of associated long-term side effects.

The current practice was inconsistent with recommended best practices; therefore, a quality improvement care process was necessary. This project's primary focus was to help patients make treatment decisions by providing accessible, evidence-based information about localized prostate cancer treatments and outcomes, pre-and post-treatment expectations, and resources to support positive coping behaviors following their chosen treatment. Decision tools provide information and resources to patients and empower and encourage them in their treatment decisions. Patients need to be well informed of all available treatment options and given time to express their values before making a final decision. Hence, this project's primary goals were patient-centered care, empowerment, decision-making, patient satisfaction, and

decreased decisional regret. A toolkit was developed using evidence from the literature to achieve the goals and to improve care. As a result, patients were expected to be more confident in their treatment decisions, to cope better and express satisfaction, even if their quality of life was compromised post-treatment. Alternatively, they may feel disempowered and uninformed, leading to the need for a second medical opinion, and dissatisfaction with their treatment decision and quality of life in the long term.

### **Environmental Context**

The project was developed, implemented, and evaluated at Hemet Valley Urology Medical Center; an outpatient clinic located in Southern California. The setting is a privately owned medical clinic consisting of three providers: two Physicians and one Nurse Practitioner. The main goal at the center is to provide holistic and personalized patient care. Current practice at the clinic is to provide brief information about the treatments available. The physician's preferred treatment choice is communicated to patients at initial diagnosis depending on their age and disease stage determined by the Gleason score. More than 80% of patients come back in a week with their decision to go along with the physician's recommendations. The office accommodates approximately five to six newly diagnosed prostate cancer patients per week in addition to patients who are affected by other illnesses. Evidence recommends that tools be used to aid general treatment decision-making, yet there is no tool or decision aid used in the current practice setting.

During the project's development and prior to its implementation, a SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis was undertaken in the practice environment. The strengths included a well-organized service with friendly staff and expert physicians and an efficient electronic medical record (EMR) system. Weaknesses included lack of shared treatment

decisions and decision-making tools/aids for patients diagnosed with prostate cancer, patients seeking second medical opinions for treatment decisions resulting in delayed treatments, lack of on-site diagnostic tools, and lack of fully interfaced diagnostics and labs. Identified opportunities included promoting best practice by developing a patient-centered approach to shared care and treatment decision-making, minimizing delays in treatment of prostate cancer by using a decision-making toolkit, and reducing the need for patients to seek second medical opinions in the treatment decision process. Other opportunities included updating technologies such as magnetic resonance imaging (MRI) recommended by the American Urological Associations (AUA) and American Cancer Society (ACS) to decide the need for repeated biopsy and greater collaboration of the multidisciplinary team involved with prostate cancer treatments. The threats were merit-based incentive payment systems that prioritize documentation more than the quality of care and non-acceptance of various insurance plans preventing treatments and follow-up care.

### **Faith Integration and Theoretical Framework**

Mollica, Underwood, Homish, Homish, and Orom (2015) conducted the first longitudinal study on the relationship between spiritual beliefs and treatment decision-making in newly diagnosed patients with localized prostate cancer. Spirituality was operationally defined as the motivational, affective, cognitive components of decision-making in life and spiritual coping. Participants were recruited from five clinical facilities, two academic centers, and three community practices in New York between 2010 and 2013. Data from questionnaires revealed that greater spirituality was associated with improved decision-making satisfaction and decreased decisional conflict and decision-making difficulty. According to Mollica, Underwood, Homish, Homish, and Orom (2015), spirituality is a set of beliefs, behaviors, and religious practices that bring peace and meaning to life. It may help people cope with the fear and shock of diagnosis

and increase the physical and mental quality of life. Awareness of spirituality provides a feeling of being supported by a higher power and recognition of the value of life. Bruce et al. (2020) found that prostate cancer significantly increases men's stress levels and impairs their quality of life. Faith can be a source of comfort and strength in the diagnosis, treatment, and survivorship of prostate cancer.

Promotion of faith and spirituality may influence coping and provide opportunities for improved outcomes in patients with prostate cancer. Integration of this author's personal faith can be a bridge to help men and their families to cope with prostate cancer. The verse in Romans 12:15 is significant, 'Rejoice with those who rejoice and mourn with those who mourn.' The second part of this verse is applied in this author's practice when providing care to the patients when they are first diagnosed with prostate cancer. At this time, although there are many treatments available, men and their families still feel unsure, overwhelmed, upset, or worried. As a follower of Christ, I choose to share the love of God in action with my patients by rejoicing with them and mourning with them.

Implementation of this project provided opportunities to calm patients' fears and reduce their stress by using a toolkit to personalize their care at a vulnerable time. This was evidenced by the findings of this project in which men responded with confidence to this writer's care which was underpinned by scripture such as Proverbs 3:5, "Trust in the Lord with all your heart and lean not on your understanding; in all your ways acknowledge Him, and He will direct your paths."

### **Theoretical Framework**

The theory used in the project is Faye Abdellah's 21 Nursing Problems Theory. Patients and families are recognized as a unit based on their physiological, psychological, social,

spiritual, and financial needs. Abdellah identified 21 typologies of nursing problems to address patient care holistically. For example, Typologies 12-21 related to a holistic approach of treatment decision-making in prostate cancer. The decision-making toolkit and nursing care were personalized to address patients' well-being from a holistic perspective. More specifically, Typologies 12 and 13 described the interrelatedness between emotions and organic illness. Therefore, during pretreatment visits, the decision-making toolkit was designed to engage patients in a discussion about their emotional responses to prostate cancer while also addressing factual information about the range of treatment options. Typology 14 referred to the facilitation of effective verbal and nonverbal communication. The toolkit was designed to help the healthcare provider and patient initiate a conversation and encourage more active participation in care. Typologies 15, 16, and 17 emphasized interpersonal relationships, personal spirituality, and a therapeutic environment. The toolkit and points of care promoted understanding of patients' values, preferences, and individual needs. Typologies 19, 20, and 21 acknowledged self-awareness as individuals with physical, emotional, and developmental needs. They also discussed the acceptance of optimum goals with physical and emotional limitations and resources to facilitate the right decisions. Abdellah's 21 Nursing Problems Theory was used to guide the development and delivery of a new patient-centered practice to improve care and outcomes for men with localized prostate cancer (Abdellah, 1961).

Abdellah's theory is applied to this project jointly with the EASSi framework (McCaughan et al., 2020). This framework was developed by using evidence-based data, semi-structured interviews, and a think-aloud method. Its components are Engagement, Assessment, Support, and Signposting and are used as a guide to help patients fully participate in their treatment decision. Patient *engagement* was encouraged at their initial appointment and



diagnosis, and the provider made them comfortable with the process by clearly and sensitively communicating factual information while acknowledging feelings and emotions. Patients were *supported* by providing evidence-based resources to help them understand treatment options and expected outcomes, including potential side effects. *Signposting* was achieved by being provided credible web links and videos to support knowledge development and as tangible resources for patients and their families to view and discuss together in their own time. These data served to address myths about prostate cancer and alleviate fears associated with detection and treatment while also advocating evidence-based data about survivorship and quality of life indicators. Finally, the EASSi framework was utilized to inform, develop, design, and test the toolkit in close collaboration with end-users to maximize the care experience of patients and their family members during this vulnerable time.

### **Literature Review and Evidence Synthesis**

#### **Search criteria**

The author conducted a systematic electronic search using CINAHL, Medline, PubMed, PsycInfo, and EBSCOhost databases to locate publications 2011- 2020. Search terms were used alone and in combination to locate relevant research in peer-reviewed scholarly journals in the English language. Keywords included prostate cancer, treatment decisions, shared decision-making, localized prostate cancer treatment, patient empowerment, patient participation, and treatment outcomes. The search strategy resulted in 21 articles for review. This data was synthesized according to commonalities and differences in methodologies, methods, and outcomes. Evidence of patients' involvement in the decision-making process, types of treatment satisfaction with the treatment choices, and the importance of tools informed the development and implementation of the project.

**Evidence synthesis and findings:**

Ilic et al. (2015) claimed that prostate cancer is a leading neoplastic disease second only to lung cancer affecting men worldwide and is the most common cancer in developed countries and the sixth common cancer in developing countries. Various treatment options are available for localized prostate cancer. The most common being radical prostatectomy, radiation therapy, and active surveillance. Disease monitoring and appropriate treatments are known to prevent metastatic disease. Andkhoie, Meyer, and Szafron (2019) and the American Cancer Society (2020) acknowledge that disease monitoring and appropriate treatments result in a tremendous reduction in 5-year localized prostate cancer progression to the metastatic stage (100% to 30%).

Following diagnosis, men needed to be decisive and must make a quick decision about treatment from various options, but making such decisions is often difficult. When they are first diagnosed, they are often in a state of shock, uninformed, under pressure, and are led by the preference of their physician. For example, Jayadevappa et al. (2020) reported that the complex nature of prostate cancer treatment, the unfamiliar conditions of diagnosis, and inadequate knowledge of treatment options resulted in most patients selecting their physician's recommendations. Lange, Trock, Gulati, and Etzioni (2017) also suggested physician's preferences are central to men's treatment choices when they are presented with a large volume of information that they must process in a short timeframe leading to increased anxiety and feelings of being overwhelmed. Going forward with a physician's opinion of treatment may be the best choice, but patients feel obliged to defer to this without being fully informed and included. Although the physician's medical opinion is essential to treatment decision-making, Lin, Aronson, Knight, Carrol, and Dudley (2010) recommend that healthcare providers should

personalize care and involve patients' families and friends in their treatment. In addition, patients are best supported by ensuring the treatment choice aligns with individual needs, values, and preferences.

Decision-making tools are suited to personalize care and support informed choices about treatment benefits, limitations, and uncertainties. According to Simmons, Brown, Haynes, Richardson, and Withers (2018), nurses play an essential role in developing and implementing shared decision-making tools that aid patients in making informed treatment decisions and providing continued education to reduce health disparities. The research demonstrated that decision-making tools and shared conversations between patients and clinicians improved decisional outcomes and facilitated greater decisional satisfaction. Various generic toolkits and aids are used to support treatment in healthcare settings, but none of these are specific to prostate cancer treatment. Zhong, Smith, Haghighi, and Mancuso (2018) compared various generic decisional tools used by eleven patients newly diagnosed with prostate cancer utilizing the decisional conflict scale developed by O'Conner (1995). Six patients used the original version of the scale, and five used a modified version. Four decisional tools significantly reduced decisional conflict at the first follow-up post-intervention proving the use of decision-making toolkits in successful decision-making.

Decision-making in localized prostate cancer involves five key factors: the type of treatment available, socioeconomic and demographic data, personal choices of the patient, psychological factors, and the degree of involvement in the decision-making process (Andkhoie, Meyer, & Szafron, 2018). According to Baker, Wellman, and Lavender (2016), men who received sufficient information about pre-and post-treatment adjusted well to expected side

effects. Orom, Biddle, Underwood, Nelson, and Homish (2016) stated that patients need to be fully informed about available treatment options, benefits, risk factors, clinical indicators, and recommendations. Increasing patients' knowledge of the disease, the risks, and the benefits of treatment significantly impact treatment decision-making. They should be provided opportunities to communicate preferences to their physicians. Ilic et al. (2015) also agreed that decision-making tools should provide information about the benefits and limitations of medical treatments to assist in the decision-making process and improve health outcomes. Periodic feedback to check the understanding of patients and follow-up on decision implementation is essential before a final decision is made.

All prostate cancer treatment options have side effects that can significantly impact men's quality of life. Treatments and their side effects impact patients' well-being (Eton, Shevrin, Beaumont, Victorson, & Cella, 2010). The common effects are sexual and urinary dysfunction, bowel dysfunction, loss of libido and hot flushes, mood disturbances, and gynecomastia (Wagland et al., 2019). Treatments such as surgery or hormone therapy to block testosterone further add the risk of erectile dysfunction. Radical prostatectomy, the standard treatment for localized prostate cancer, causes erectile dysfunction in 10 to 100% of patients due to nerve injuries by intraoperative nerve traction, thermal damage, ischemic injury, and local inflammatory reactions. Radiation therapy leads to sexual dysfunction in 20 to 80% of patients by causing harm to the nerves; brachytherapy accounts 10 for 90% of patients with erectile dysfunction. Cryosurgery may cause cryogenic injury of the neurovascular bundle near the prostate, leading to sexual dysfunction and inhibiting the proliferation of prostate cancer cells. Necrosis blocks the actions and synthesis of testosterone androgen deprivation therapy, causing significant problems with erectile dysfunction (Hyun, 2012).

When considering individual preferences and the most common side effects, it is imperative to provide a secure and professional approach to initiate discussions about sexual issues. Providers must be prepared for further conversations to ensure all men were supported with sexual well-being. They enhanced coping with sexual dysfunction by addressing individual concerns through a concise conversation and explaining the relationship between sexual functioning and prostate cancer (McCaughan et al., 2020; Spindel, Joubert, Lee, & Fairhurst, 2017).

In summary, this literature review highlighted evidence in three key areas proving the need for effective communication about complex treatment. The necessity for patient-centered approaches to care that promote informed and confident treatment decisions and the effectiveness of tools/decision aids to facilitate a patient-centered approach to treatment decision-making may mitigate decision regret and enhance long-term well-being. Each of these key areas will be discussed in the context of this project: shared decision-making in prostate cancer treatment.

### ***The complexity of treatment and effective communication***

A qualitative study conducted by Thera, Carr, Groot, Baba, and Jana (2018) with eleven patients demonstrated the complexity of the decision-making process in prostate cancer treatment. The availability of efficacious and complex treatment options urged men to seek a shared decision-making process with their health care team. The patients and health care professionals collaborated with nurse navigators in shared decision-making to increase knowledge, decrease indecision, and reassure patients when they felt overwhelmed. Active surveillance, radical prostatectomy, and radiation therapy with external beam or radioactive seed

implantation into the prostate (Wang & Ranasinghe, 2018) are standard treatment options for localized prostate cancer. Patients with low and intermediate risk are offered active surveillance, radical retropubic prostatectomy, external beam radiation therapy, and brachytherapy. Radical surgery or radiation therapy is the treatment choice offered for men with high-risk prostate cancer. Androgen deprivation therapy is an adjuvant to radiation therapy offered to men diagnosed with intermediate and high-risk localized prostate cancer (Baker, Wellman, & Lavender, 2016). Shared decision-making enabled patients to use their autonomy to make their treatment choice when providers respected patients' values and concerns and facilitated an understanding of the benefits and potential complications to reduce decisional regret. So, it is imperative to relay treatment information with accuracy and sensitivity to promote informed consent and patient confidence in their choice. Moreover, shared decision-making improves health outcomes, patient and provider satisfaction, and patient adherence to treatments using available healthcare resources more effectively (Colella & DeLuca, 2004).

### ***Patient-centered approach to care***

The availability of multiple and equally effective treatments increases decision-making uncertainty and anxiety in addition to prostate cancer diagnosis and shock. Patient-centered care enables men to articulate and voice their preferences and priorities in the choice of treatment (Wagland et al., 2018). The optimal decision relies on individual preferences for outcomes and the treatment values that matter to that individual. Measuring specific attributes that matter to patients' personal values, and identifying immediate care goals enhance a patient-centered approach (Saigal, Lambrechts, Srinivasan, and Dahan, 2016). According to Scherr et al. (2016), prostate cancer is a personal preference-sensitive diagnosis; and patient preferences and

functional outcomes are important considerations during the treatment decision process. Dew, Signal, Stairmand, Simpson, and Sarfati (2018) used audio-recordings of cancer care consultations with eighteen patients, their support people, and medical specialists and followed up with interviews. After analyzing the impact on decision-making, they concluded that the consideration of patients' preferences and provision of ample time to exercise their rights when deciding on treatment led to optimal treatment outcomes. In addition, patients who are encouraged to collaborate with their physicians demonstrate less fear and increased satisfaction with the decision they reach (Andkhoie, Meyer, & Szafron, 2018).

Patient education and empowerment in treatment decisions and patient-centered communication with the patient, family, and friends is essential for improving treatment outcomes. Ganz (2014) suggests priority should be given to the coordination and integration of care and providing emotional support to relieve the fear of treatment outcomes for prostate cancer patients. Treatment decision-making can be overwhelming for men diagnosed with localized prostate cancer, and decisions are made wholly on men's preferences for optimal outcomes, according to Saigal, Lambrechts, Srinivasan, and Dahan (2016). Patient-centered communication and shared decision-making help people make an informed choice of treatment when provided with adequate information about the disease condition, including the cost of treatment, probabilities of outcomes, and various health risk factors. Jayadevappa et al. (2015) concluded in a mixed-methods study that assessing patient preferences is crucial for optimal treatment and engaging patients in informed decision-making. Doing this improves treatment choice and quality of care. Better outcomes depend on the care that focuses on a patient's individual needs, values, and decisions (Rose, 2018). Confidence in individual choice resulted in better survival rates and quality of life outcomes when men received evidence-based information

and were personally involved in choosing their treatment option (Baker, Wellman, & Lavender, 2016). In summary, evidence suggests a patient-centered approach to care enables men and their families to be active participants and maximizes medium and longer-term health outcomes. Therefore, patient-centered care should be considered the best nursing practice for men diagnosed with localized prostate cancer.

### ***Effective use of tools and decision aids***

Decision-making tools/aids facilitate increased patients' knowledge about treatment options during the limited time of initial clinical consultation. The provision of essential guidance and coaching are essential components of any decision-making tool (Ilic et al., 2015). The successful implementation of a decision-making toolkit increases the patient's knowledge and confidence, improves their decision-making process, decreases decisional conflict, and meets population needs (Ilic et al., 2015). A systematic review conducted by Zhong, Smith, Haghighi, and Mancuso (2018) revealed that decision-making tools guide the step-by-step decision-making process increasing patients' knowledge level, decisional control, and decisional satisfaction, thereby decreasing decisional conflict and regret. Oswald et al. (2020) observed that patients and providers make a collaborative treatment decision based on clinical information, available treatments, risks, benefits, costs, and patient's values and preferences. A mixed-methods study with fourteen cancer survivors in three focus groups at Vanderbilt University Medical Center (VUMC) determined that many professional societies recommend shared decision-making as the ideal approach in prostate cancer treatment due to the complex nature of treatment options, (Oswald et al. 2020).



Evidence suggests that decision-making toolkits increase patients' knowledge, improve confidence, and empower them in treatment decision-making. A shared process facilitates informed treatment decisions with minimal conflicts and improves the quality of life after treatment (Nanton et al., 2018). A population-based mixed-method study in the U.K. by Wagland et al. (2019) revealed that patients' knowledge and understanding of prostate cancer, availability of treatments, valuing individual preferences, and their involvement in the process empower them with confidence in treatment decision-making. Further evidence from an Australian study by Wang and Ranasighe (2018) supports the view that patients prefer to make autonomous treatment decisions when relevant information, treatment efficacy, and long-term side effects are explained. Thus, generic decision-making toolkits assist in ensuring high-quality treatment decisions for patients with prostate cancer. Furthermore, the use of the toolkits improves care in the critical domains of patients' knowledge, active participation, personal satisfaction with their decision, and selection of final treatment (Lin, Aronson, Knight, Carrol, & Dudley, 2010).

In addition to published literature, clinical experts support decision-making toolkits or aids for best practice prostate care. At a recent Prostate Cancer Summit, several keynote speakers advocated for developing and using a decision-making toolkit or decision aid specific to men with localized prostate cancer (Prostate Cancer Summit, 2021). Research evidence and clinical practice experts strongly recommend implementing a shared decision-making toolkit in prostate cancer treatment to support treatment decisions, coping, and improved health outcomes.

### **Project Objectives/Outcomes**

The main objectives identified before implementing the project included specific outcomes to achieve with short-term and long-term goals. The main objectives are described below:

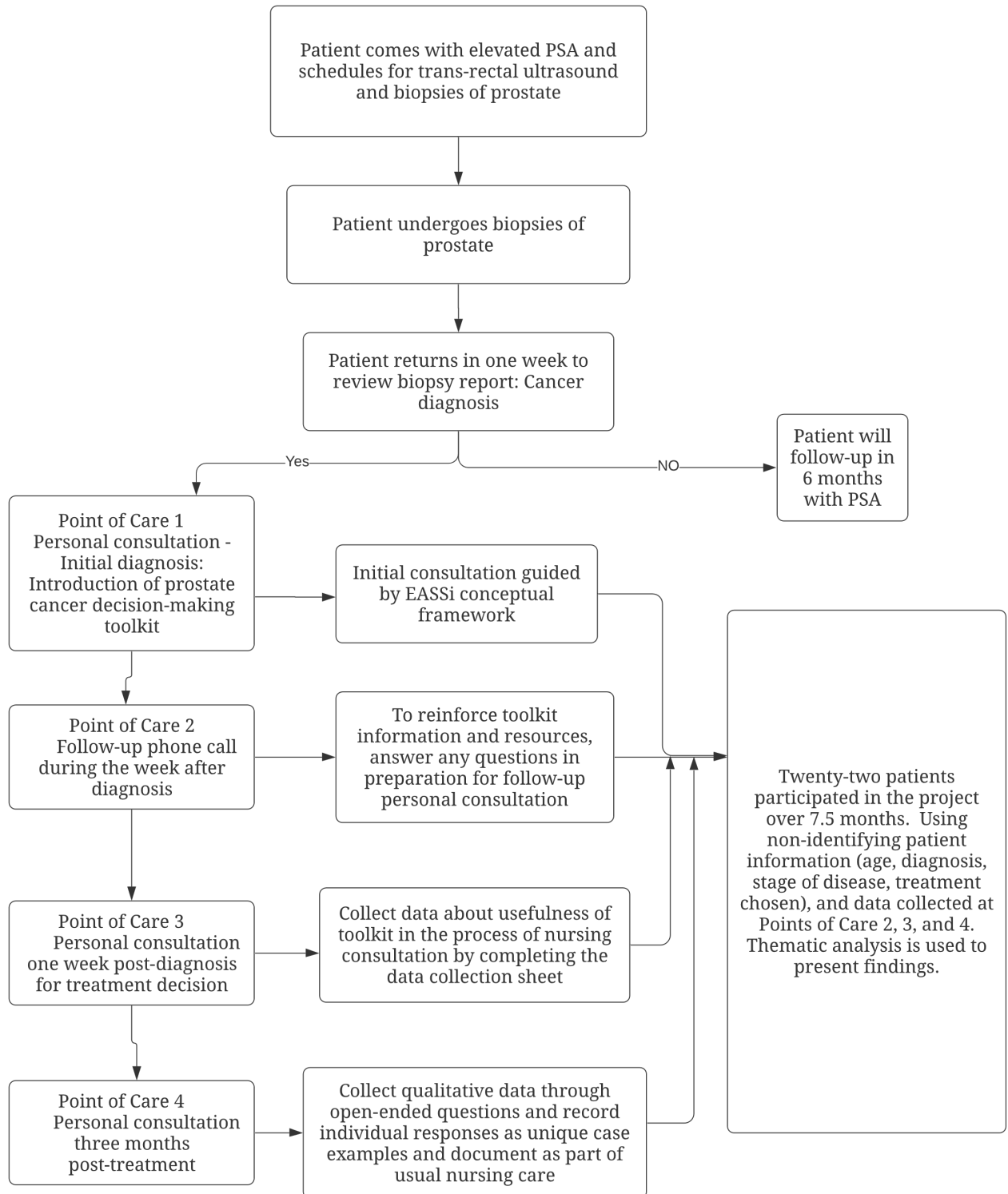
- By September 2020, providers at the facility evaluated the draft evidence-based treatment decision-making toolkit, provided formative feedback, and made necessary changes to improve the toolkit before implementing the tool with prostate cancer patients.
- By November 2020, began implementation of the treatment decision-making toolkit to all patients with prostate cancer between the ages 40-79 years to promote shared decision making.
- By March 2021, the author evaluated patient satisfaction with their treatment decision process using the decision-making toolkit at four points of care from September 2020 to the end of June 2021.
- At the conclusion of the project, the author determined how many patients sought a second medical opinion before their treatment decisions and any resulting delays in treatment.

The purpose of these various short-term goals was to develop and implement a patient-centered shared decision-making process, develop patient confidence in their treatment decision by using the toolkit, increase awareness and knowledge of the complex nature of treatments and expected outcomes to promote confidence in treatment decisions and cope, and empower shared decision-making with a better understanding of short-term and long-term benefits and side effects of treatment. The primary long-term learning goals to achieve were patients express satisfaction with their prostate cancer treatment choice and patients express satisfaction with their ability to cope post-treatment.

The Project Overview and process of care are represented below in Figure 1.

Figure 1

## Project Overview



### **Methods and Implementation**

Approval for the project was given by California Baptist University Institutional Review Board (9.22.21, Appendix 1). Qualitative questions at each point of the four points of care were used with a convenience sample of twenty-two patients. Informal and structured questions with verbal and nonverbal responses at points of care two, three, and four were recorded for individual patients. The inclusion criteria were that all newly diagnosed localized prostate cancer patients were between 40-79 years. The exclusion criteria were patients over 80 years and patients with metastatic disease.

Following approval, the author met the first objective by developing an evidence-based toolkit. The toolkit included basic information on the anatomy of the prostate and its function, prevalence of disease, risk factors, diagnostic measures, treatment options, side effects and management, life after treatment, available support groups, and evidence-based videos and web links (Appendix 2). This final draft completed by September 2020, was developed in collaboration with service providers' expert evaluation and feedback. Changes were made based on this evaluation, and the toolkit was approved for implementation in practice. Objective 2 was met in November 2020 when the toolkit was introduced to newly diagnosed patients as part of a nurse-led decision-making process.

### **Implementation**

Each patient initially presented for a prostate biopsy and was scheduled to return one week later for pathology results. During the return visit, patients with positive results were introduced to the toolkit at the first point of care using the EASSi framework as a practice guide. Patients went home with the toolkit to assist them with their treatment decision. At the second point of care, during the following week, each patient received a phone call for follow-up

support, at which time the information and resources in the toolkit were reiterated. It was explained to the patient that the toolkit was to help in shared decision-making. Patients were asked about their experience using the toolkit, and any questions relating to their care were addressed. Patients returned to the clinic one week after diagnosis at the third point of care to discuss their treatment choice. Three months post-treatment, patients were seen in-person for consultation and evaluation at the fourth point of care. At points of care two, three, and four, patients were asked open-ended questions to elicit responses about their experience using the toolkit to make a treatment choice and their confidence and satisfaction with their decision. Data collection was informed by developing open-ended questions asked of each patient at three points of care, as shown in Table 1.

## Qualitative Questions at Points of Care

Table 1

| <b>Point of Care 1:</b><br>At diagnosis.   | <b>Point of Care 2:</b><br>Follow-up phone call during the week after diagnosis.   | <b>Point of Care 3:</b><br>Personal consultation one week post-diagnosis.  | <b>Point of Care 4:</b><br>Three months post-treatment.  |
|--|--|--|--|
| Introduction of the toolkit:<br>Implementation as part of nursing care guided by EASSi conceptual framework. | What questions do you have?<br><br>What is most important for you now?<br><br>Is there anything I can do for you before we meet next week? | Can you tell me how you came to make your decision?<br><br>In what ways was the toolkit helpful (or unhelpful) in making your decision?<br><br>What was most beneficial for you? Why?<br><br>How confident are you in your decision? | Tell me about your experience of treatment and how you have managed since then?<br><br>In hindsight, do you think you made the best treatment decision? Why? Why not?<br><br>Are you satisfied with the decision you made? Why? Why not?<br><br>Knowing what you know now, would you do anything differently?<br><br>What advice would you give someone else who was in a similar situation? |

### **Finances and Resources**

This project's cost involved preparation time and printing of the toolkit. The project was made cost-effective by training providers during the available break times during the Corona Virus Pandemic. The toolkit was made accessible for all patients; the product is free of cost to anyone affected by prostate cancer. Labor charge to make a treatment decision-making tool:

Create the document:  $\$60/\text{hour} \times 6 = \$360$  (Documents created during normal working hours).

The workplace did not pay any additional costs for the creation of the tool. Printing costs: Print 100 copies  $\$0.50/\text{page} = \$50$ ; eight toolkits were printed and given to clients per month.

Training/In-service Training for providers to use the tool  $\$75/\text{hour} \times 8 \times 2 = \$1200$ ; two providers trained for 8 hours each. Extension of visits: Provision of the tool in practice extend each visit by an additional 30-minute  $\times 3$  times per patient  $\$150 + \$75 \times 8 = \$750 \times 3 = \$2250$ .

Eight patients per month with an extra 30 minutes with each visit to explain the toolkit.

Description cost breakdown of total revenue with explanation:

Avoidance cost was achieved by reducing return visits to clarify treatment options before final decisions and were brought down to two instead of three visits for eight patients per month:  $\$150 + 75 \times 8 = \$750 \times 2 = \$1500$ .

### **Final Results and Outcome Analysis**

#### **Final results**

Qualitative responses from patients at each point of care were recorded on a data sheet. Additionally, non-identifying demographic information was documented to describe participants during the project (age, diagnosis, stage of disease, the treatment chosen, and if they sought a second medical opinion). Twenty-two patients participated in the decision-making process using the toolkit. Of those twenty-two patients diagnosed with prostate cancer, twelve patients decided

to proceed with surgical treatment, six of them chose radiation treatment, two patients decided to have hormone treatment, and two opted to be on active surveillance. The average age of patients who chose prostatectomy was 64 years, the average age of men who decided to have radiation was 70 years, patients who chose to have hormone treatment were 81 years of age, and the men who opted for active surveillance were 73 years. None of the twenty-two patients chose to seek a second medical opinion before making their decision. Table 2 represents the demographic data of the analysis.

Demographic Data of Analysis  
Table 2

| <b>The average age in years</b> | <b>Average Gleason Score (Out of 10)</b> | <b>Treatment chosen</b> | <b>Sought second medical opinion</b> |
|---------------------------------|--|-------------------------|--------------------------------------|
| 64                              | 7-8                                      | Surgery                 | None                                 |
| 70                              | 6-7                                      | Radiation               | None                                 |
| 81                              | 8  | Hormone therapy         | None                                 |
| 73                              | 6  | Active surveillance     | None                                 |

According to Sandelowski (2000), data collection is directed toward gathering who, what, how, and why of events or experiences using minimally to moderately structured open-ended individual and focus group interviews a day-, week-, month-, or year-in-the life approach of actual persons or case studies. Qualitative data were recorded as individual case studies for each patient at the three points of care. A case study approach was appropriate to this project because this sought to answer 'how' and 'why' questions consistent with Sandelowski's recommendation for representing verbal and visual data. Braun and Clarke (2006) described the purpose of thematic analysis to identify, analyze, and report patterns within data by organizing and describing the data set in detail. The author recorded individual patient responses to open-ended questions on a data sheet. Aggregate data were further analyzed using Braun and Clarke's methods to identify and report patterns within the data, including 1) Familiarization with the



data, 2) Generation of initial codes, 3) Identifying patterns and themes, and 4) Reviewing the themes and producing a report (Braun & Clarke, 2006).

### **Outcome Analysis**

The toolkit was introduced to patients as part of the process of care at Point of Care one. Findings were presented for qualitative data relating to Points of Care two, three, and four. The analysis at each point of care was recorded in a datasheet using various questions using patients' verbal responses. Direct responses from individual patients were chosen as evidence that best represents all participants, identified the similar themes and individual responses, and organized into multiple groups.

#### **Point of Care 2: At follow-up phone call:**

Question 1. What questions do you have?

Most patients acknowledged they did not have any questions as they were currently reading and using the toolkit. However, several patients' responses indicated they were hesitant to begin the process relating to the shock of diagnosis. For example, "It was really hard to understand the treatment options as I was alone to receive the devastating news of cancer" (Patient 9).

Similarly, patient 5 responded, "I did not hear anything that was discussed; I was in a shock to receive the diagnosis and was looking at my daughter's face to see her reaction."

Patient 11 stated, "The news was difficult; I did not expect it because my PSA was not that high. I did not hear half of what was discussed; my mind was wandering."

The follow-up phone call was an encouragement in the process of decision-making, evidenced by the example of patient 6 "To be frank, I did not want to read the toolkit after I heard that I have cancer, but I am going to read it today."

Question 2. What is most important for you now?

In response to this question, patients expressed how important it was that they take time to use the toolkit during the week:

Patient 3 expressed, “My wife and I are still going through the toolkit; we do not want to rush to make the decision.”

“I want to go through the toolkit to understand more about treatment” (Patient 6).

In addition, others indicated how helpful it was to review the toolkit information as a couple and to process their treatment options together. For example, Patient 2’s wife stated, “We were able to understand why the doctor chose this particular treatment for him.”

Question 3. Is there anything I can do for you before we meet next week?

Patients were positive in response to this question, indicating their understanding of the toolkit information and confidence in their decision at Point of Care 3.

Patient 10 responded, “No, I understood my treatment choice and why.”

Similarly, patient 4 stated, “Not really, the toolkit explained it well.”

Patient 15 also said, “We read the toolkit information and felt we are on the right track with treatment.”

**Point of Care 3: In-person consultation:**

Question 1. Can you tell me how you came to make your decision?

Patients expressed their knowledge of what treatment involved and understanding about what to expect with their treatment choice. “I was all determined to remove the prostate, but the toolkit explained that if I choose any other treatment, it would not be possible to do surgery” (Patient 4).

In addition, patient 16 reiterated, “The toolkit gave me assurance explaining in simple and

understandable language.”

The response of patient 9 was, “My wife and I took enough time to read the toolkit and watched videos to understand the treatment options to make my treatment choice.”

Question 2. In what ways was the toolkit helpful (or unhelpful) in making your decision?

“It was very comforting to know that this cancer can be treated and has a reasonable survival rate. I felt comfortable going ahead and taking the treatment decision that the doctor suggested” (Patient 8).

In addition, patient 7 stated, “I was delighted to learn that I have many choices and what choices.”

Similarly, patient 17 responded, “The toolkit actually helped me to understand more about my disease and gave me the confidence to go with treatment.”

Question 3. What was most beneficial for you? Why?

Patients agreed that the toolkit was presented well, easy to understand, and the web links of videos were beneficial. “The treatment options, as well as the videos, were very helpful to know more about my options” (Patient 14).

Patient 18 reiterated, “The videos were very clear to follow, and I felt at ease after watching the videos.”

In addition, patient 22 expressed, “To know about what to expect after treatment and the various coping mechanisms were beneficial.”

Question 4. How confident are you in your decision?

All patients responded that they were confident to make their treatment decision.

Patient 3 stated, “We were educated after going through the toolkit and confident to go with treatment.”

Another patient, 20, also expressed, “The knowledge about treatment, the survival rates, and the videos gave me the confidence to make my treatment decision.”

Similarly, patient 9 stated, “The detailed information about the treatment and aftereffects gave me the confidence to choose the treatment.”

**Point of care 4:** In-person consultation three months post-treatment visit:

Question 1. Tell me about your treatment experience and how you have managed aftereffects and adverse reactions, if any, after treatment?

Some patients expressed that they had a thorough understanding of the aftereffects of treatment. Therefore, they expressed an ability to cope with the changes in the quality of life they experienced.

For example, patient 12 responded: “The toolkit was a good guide to understand what to expect and made it easy to go through the new journey.”

Patient 17 also stated, “To know more on what to expect after treatment and aftercare, especially monitoring the PSA.”

Similarly, patient 14 said that “I felt better informed about managing his health in the longer term.”

Question 2. In hindsight, do you think you made the best treatment decision? Why? Why not?

All patients agreed that they were confident with their treatment decision. “I am very confident with my treatment decision” (Patient 6).

Patient 11 responded, “The toolkit helped me to understand what treatment is suitable for me.”

The response of patient 13, “I am confident that I made the right decision because toolkit helped to understand all about my disease and treatment.”

Similarly, patient 9 stated, “The toolkit helped me to learn what is involved in the treatment, and I feel I made the right decision about my treatment.”

Question 3. Are you satisfied with the decision you made? Why? Why not?

Many patients responded that they were delighted with the treatment decision as the toolkit informed them of what to expect after treatment.

Patient 5 expressed, “The toolkit gave me enough confidence to make an informed decision.”

The response of patient 15, “I am confident that I made the right treatment decision with the help of toolkit. The videos were informative.”

In addition, “The toolkit helped to understand the reasons of my treatment choice, and I am satisfied to go with the treatment option that was suggested.” (Patient 3)

Patient 18 stated, “The toolkit helped me to understand my treatment options and post-treatment expectations to cope better, giving me the confidence to take the treatment.”

Patient 22 expressed, “The videos in the toolkit increased my understanding of my disease and felt very comfortable to get treatment.”

Question 4. Knowing what you know now, would you do anything differently?

The responses were satisfying as all patients agreed that they would not choose any other treatment.

Patient 2 responded, “The toolkit gave me the reasons for my treatment choice, and I would not choose any other treatment.”

The response of patient 7 reiterated, “I gained the confidence with the treatment decision after reading the toolkit as to why I was given this option.”

In addition, patient 11 also stated, “The toolkit helped me to understand my treatment choice well and post-treatment expectations.”

Similarly, patient 19 reiterated, “The toolkit gave me enough confidence to make an informed decision.”

Patient 22 also expressed, “The information and the videos in the toolkit gave me the confidence to make my treatment decision.”

Question 5. What advice would you give someone else who was in a similar situation?

The expressions to this question provided confidence in understanding disease and monitoring the PSA for early detection and treatment.

Patient 17 said, “As this is the first time going through this kind of treatment, the toolkit also helped us with what to expect after treatment. It informed us about checking our sons’ PSA levels.”

Similarly, patient 7’s response was, “My disease and treatment using shared decision-making toolkit not only did the process of care myself, but the experience also informed the care of family members.”

In summary, all twenty-two patients expressed positive feedback about the toolkit and their experience of care and decision-making. They were pleased with their treatment decisions and their ability to cope with expected side effects. They demonstrated positive engagement throughout the process, and of particular interest, no patients sought a second medical opinion, which might otherwise have resulted in a delay in cancer treatment. They expressed that the information on survival rate and treatment options was comforting. The toolkit enabled them to make educated decisions, and the resources were helpful and presented in a way that contributed to their knowledge about prostate cancer and confidence in the treatment options they chose.

In addition to these data at the points of care, the project's design sought to address and mitigate decision regret identified in the literature. Consistent with the literature, the following

example represents one patient's experience of decision regret through previous treatment at another provider and prior to participation in this project.

### **A case study on decision regret**

A 68-year-old male recently moved to the area to be closer to his family. At his initial consultation to re-establish care, he explained that he was diagnosed with prostate cancer four years ago. At that time, he felt incapable of making a treatment decision because he was shocked by the diagnosis of prostate cancer, and he did not have access to information about the range of treatment options. His former physician had recommended radiation which he agreed to. The patient expressed that he was unaware of the side effects of treatment, and he would have made other choices if he were informed and integrated into the process of treatment decision-making. He expressed a deficit in his quality of life even though he underwent treatment because he has suffered unexpected side effects and other longer-term health issues related to his treatment. He articulated regret about his treatment decision and described this as a missed opportunity to have made the personal choice for him. He stated that if his former physician had informed him about the option of surgical treatment, he would have likely chosen that instead of agreeing to radiation.

Evidence is clear that decision regret and a perceived reduction in quality of life are more likely if patients are not adequately informed and included in the decision-making process (Zhong, Smith, Haghighi, & Mancuso, 2018).

This second case study represents one patient's care experience during the project at each point of care.

**A case study on patient satisfaction**

A 64-year-old patient was diagnosed with prostate cancer. Upon diagnosis (Point of Care 1), he stated that he had already decided on his treatment. The toolkit was presented at this time and explained in detail. During the follow-up phone call (Point of Care 2), the patient stated the information was beneficial; it provided detailed information on various treatment options and criteria for choosing a specific treatment. He stated that he appreciated the information about expected treatment outcomes, which he had been unaware of. He returned in one week with confidence in his treatment choice as the toolkit empowered him to make that informed decision (Point of Care 3). The patient stated he was well informed, empowered, and confident that he made the right treatment choice. He appreciated being made aware of the treatment outcomes and post-treatment expectations, how to cope with the expected side effects, the importance of follow-up, and the explanation of the role of genetics in prostate cancer. He underwent treatment successfully and returned three months post-treatment (Point of Care 4), at which time he expressed his gratitude for receiving the toolkit and the nursing process that guided him through his care. He described how he spread his new knowledge of prostate cancer to his friends, to whom he explained the importance of PSA screening, early detection of disease, and timely treatment. He was very confident in his decision, and he also shared the toolkit with one of his coworkers diagnosed with prostate cancer.

This case represents many other participants who expressed similar experiences throughout their care using the toolkit, confirming the evidence that shared decision-making improves health outcomes, patient and provider satisfaction, and patient adherence to treatments using available healthcare resources more effectively (Colella & DeLuca, 2004).



An additional observation was that no patients sought a second medical opinion, and there was no delay in treatment decisions or treatments after implementing the project. On the contrary, all patients expressed that the decision-making toolkit helped them decide their treatment options without conflicting thoughts.

### **Implications for Practice**

Nurses play an essential role in developing and implementing decision-making tools that help patients make informed treatment decisions. A holistic approach to the care process in shared treatment decision-making increased decision satisfaction and decreased decision conflict. Continuing education with patients improves their ability to cope with expected treatment outcomes post-treatment (Simmons, Brown, Haynes, Richardson, & Withers, 2018). The role of reducing health disparities and improving quality of life outcomes challenges nurses to continue their passion in educating patients and families for decision-making with the use of evidence-based decision aids. The author is the only nurse using the toolkit in her current workplace, and the use of the toolkit was limited to this one facility. Considering these limitations of this study brings an opportunity for nurses to do further research in the future and expand the use of the toolkit in men diagnosed with localized prostate cancer. Educating future nurses about the importance of the decision-making toolkits to empower patients for making educated decisions will increase quality life outcomes and avoid decision regrets in healthcare.

### **Conclusion and Recommendations**

The purpose of this project was to develop a shared decision-making toolkit and implement it at a local urology center to empower patients to make educated decisions about treatment choices for men newly diagnosed with localized prostate cancer. The toolkit was developed in collaboration with providers at the Center. The process of care was informed by

Faye Abdellah's 21 Nursing Problems Theory and the EASSi framework of engaging, assessing, supporting, and signposting. Implementation occurred at four points of care, during which individual case study data were collected and documented in response to open-ended questions. These data were analyzed using Braun and Clarke's analytic framework, and findings were presented using direct evidence from patient responses.

All objectives of this project were met. Patients expressed positive responses throughout the process; the toolkit increased their knowledge and empowered them to make treatment decisions with which they felt confident, evidenced by all twenty-two patients expressing decision satisfaction and no patients indicating decision regret. In addition, no patients sought a second medical opinion which meant there were no delays in receiving treatment.

The physicians at the Center were involved in the project by recommending the toolkit to patients at their time of diagnosis. They have observed the benefits of integrating the toolkit into practice at each point of care evidenced by patients' appreciative comments and confidence in their treatment decisions. The project's success has led to the recommendation that the toolkit and nurse-led interventions become part of routine care at the Center with the full support of the physicians. Findings will be disseminated through American Urological Associations, academic journals, and education opportunities at other centers and local professional groups.

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## Appendices: Appendix 1

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Wednesday, July 7, 2021 at 21:58:59 Pacific Daylight Time

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**Subject:** IRB # 012-2021 DNP Approval

**Date:** Tuesday, September 22, 2020 at 8:52:03 PM Pacific Daylight Time

**From:** Institutional Review Board

**To:** Jessy Moncy Johnson, Institutional Review Board

**CC:** Jeffrey Gage, Lisa Bursch

**RE:** IRB Review

**IRB No.:** 012-2021 DNP

**Project:** Shared Decision-Making in Localized Prostate Cancer Treatment

**Date Complete Application Received:** 09/19/2020

**Date Final Revision Received:** N/A

**Principle Investigator:** Jessy Johnson

**Co-PI:** N/A

**Faculty Advisor:** Jeffery Gage

**College/Department:** CON

**IRB Determination:** DNP Application **Approved** – Faculty research using anonymous survey questionnaires; no minor participants; no more than minimal risk/risk appropriately mitigated; no deception utilized; acceptable consent procedures and documentation; acceptable data protection procedures. Data collection may begin, in accordance with the final submitted documents and approved protocol.

**Future Correspondence:** All future correspondence about this project must include all PIs, Co-PIs, and Faculty Advisors (as relevant) and reference the assigned IRB number.

**Approval Information: (Expiration: Full Review Only)** Approval is granted for one year from date below. If you would like to continue research activities beyond that date, you are responsible for submitting a Research Renewal Request with enough time for that request to be reviewed and approved prior to the expiration of the project. In the case of an unforeseen risk/adverse experience, please report this to the IRB immediately using the appropriate forms. Requests for a change to protocol must be submitted for IRB review and approved prior to implementation. At the completion of the project, you are to submit a Research Closure Form.


**Researcher Responsibilities:** The researcher is responsible for ensuring that the research is conducted in the manner outlined in the IRB application and that all reporting requirements are met. Please refer to this approval and to the IRB handbook for more information.

**Date:** 09/22/2020

## Appendix 2: Decision-making Toolkit

# PROSTATE CANCER


## Take Time to Decide



Most prostate cancers grow slowly, and don't cause any health problems in men who have them. A PSA test may find a prostate health problem. Treatment can cause serious side effects. Take time to ask your doctor these questions before you decide to get tested or treated for prostate cancer.


### Who has a higher risk for prostate cancer?

- Men who are 50 years old or older.
- African-American men.
- Men whose father, brother, or son had prostate cancer.




### What is the PSA test?

- Your prostate makes a substance called prostate-specific antigen (PSA).
- The PSA test measures the PSA in your blood.
- Your PSA level can be high for many reasons.



### What happens next if my PSA is high?

- Your doctor may repeat your PSA test.
- Your doctor may send you to a specialist (urologist) for more tests, like a **biopsy**.



Tiny pieces of prostate tissue are removed using small needles and checked for cancer cells. Biopsies are the only way to know if you have prostate cancer.



### What are my choices if a biopsy shows early prostate cancer?

**Watching it closely.**

- Get PSA tests and biopsies regularly.
- Talk to your doctor if you have symptoms like trouble urinating, blood in your urine, or pain in your back, hips, or pelvis that doesn't go away.


**Getting other treatments after talking to your doctor.**

- You may talk surgery to remove the prostate, radiation therapy, or hormone therapy.
- You may also talk about the side effects of treatment like impotence, loss of bladder control, and bowel problems.

For more information about prostate cancer:  
<http://www.cdc.gov/cancer/prostate/>

National Center for Chronic Disease Prevention and Health Promotion  
Division of Cancer Prevention and Control



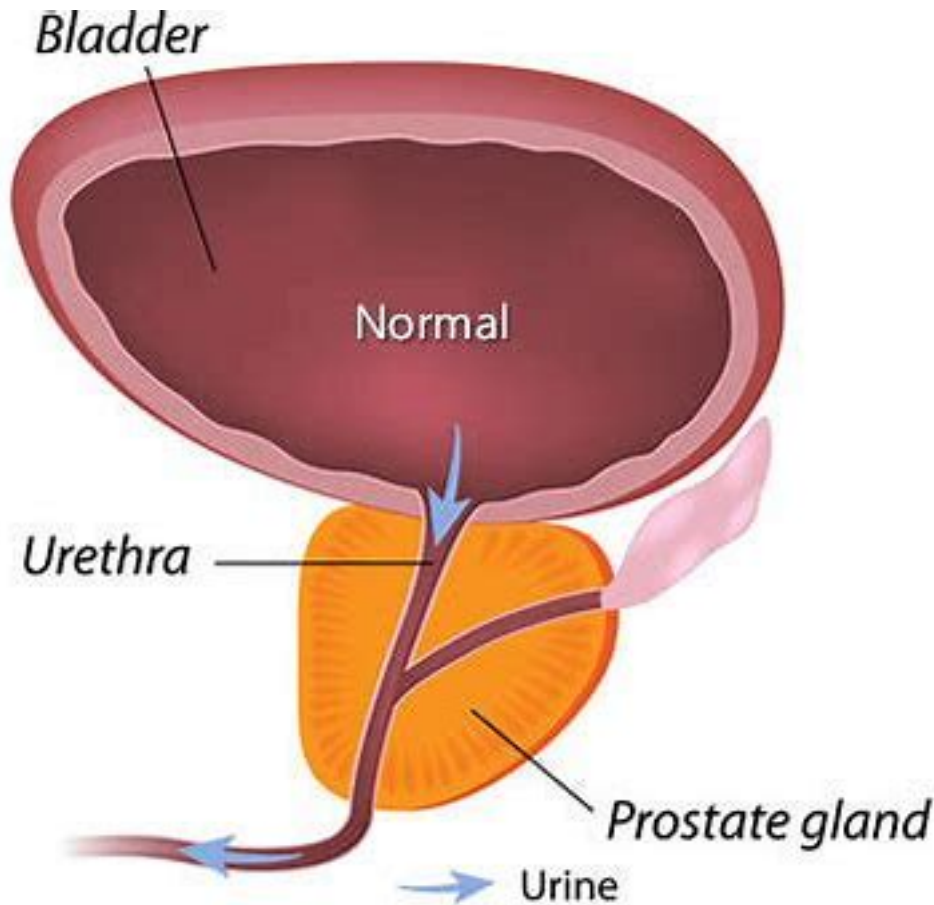


**About the toolkit:** This toolkit is for men who are newly diagnosed with prostate cancer. The tool can be used by you, your partner, family, and friends. It explains prostate cancer, the diagnostic tests used to detect prostate cancer, the treatments available with side effects / expected outcomes, and evidence-based resources.

A prostate cancer diagnosis can be scary, overwhelming, stressful, and even make you angry. When you are told you have cancer, it might be complex for you to take in all the information, and your mind will be wandering with many questions: What is prostate cancer? Is it curable? Is there a definite treatment? What will my future look like? How is it going to affect my family? How long do I live?

Now that you have been diagnosed, it is essential to understand the disease, treatment options with expected outcomes and make an informed decision about your next steps.

This toolkit explains the basics of prostate cancer diagnosis, diagnostic tests, treatment options with expected outcomes and provides evidence-based resources to support you.

**Prostate Cancer Basics**

The prostate gland is the size and shape of a walnut located below the bladder, situated around the urethra, behind the base of the penis, and in front of the rectum. The primary function of this gland is to produce seminal fluid to protect, support, and transport sperm, and the gland naturally grows more prominent as you get older.

More than 50% of men are diagnosed with low-risk disease containing cancer within the prostate gland, causing no harm or problems or symptoms. Some could be aggressive, spreading to the other parts of the body. More than 3.1 million prostate cancer survivors in the United States today give hope for a long and healthy life if diagnosed and treated early in life.

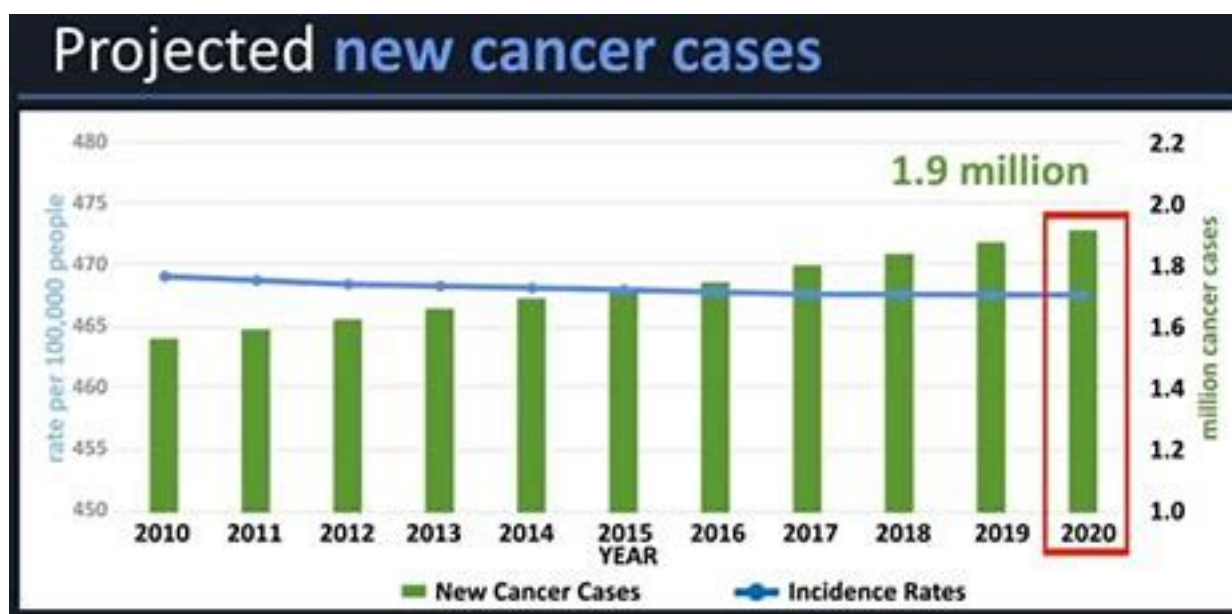
## What is prostate cancer?

Cells grow and die, replacing them with new cells in everyday cellular life. In prostate cancer, normal cells change and grow to form a tumor. Only men develop prostate cancer because only men have prostate glands. Prostate cancer is the most common cancer diagnosed in American men.

Learn more by visiting the link below.

<https://www.cancer.org/cancer/prostate-cancer/about/key-statistics.html>

## Statistics and risk factors



(CDC, 2020)

Knowing how many men are affected by prostate cancer and the contributing risk factors will help you understand and cope with your diagnosis.

- Prostate cancer is the most common cancer in American men, second only to skin cancer.

- The American Cancer Society estimates prostate cancer rates in the United States.

In 2020 there were:

- About 191,930 new cases of prostate cancer
- About 33,330 deaths from prostate cancer

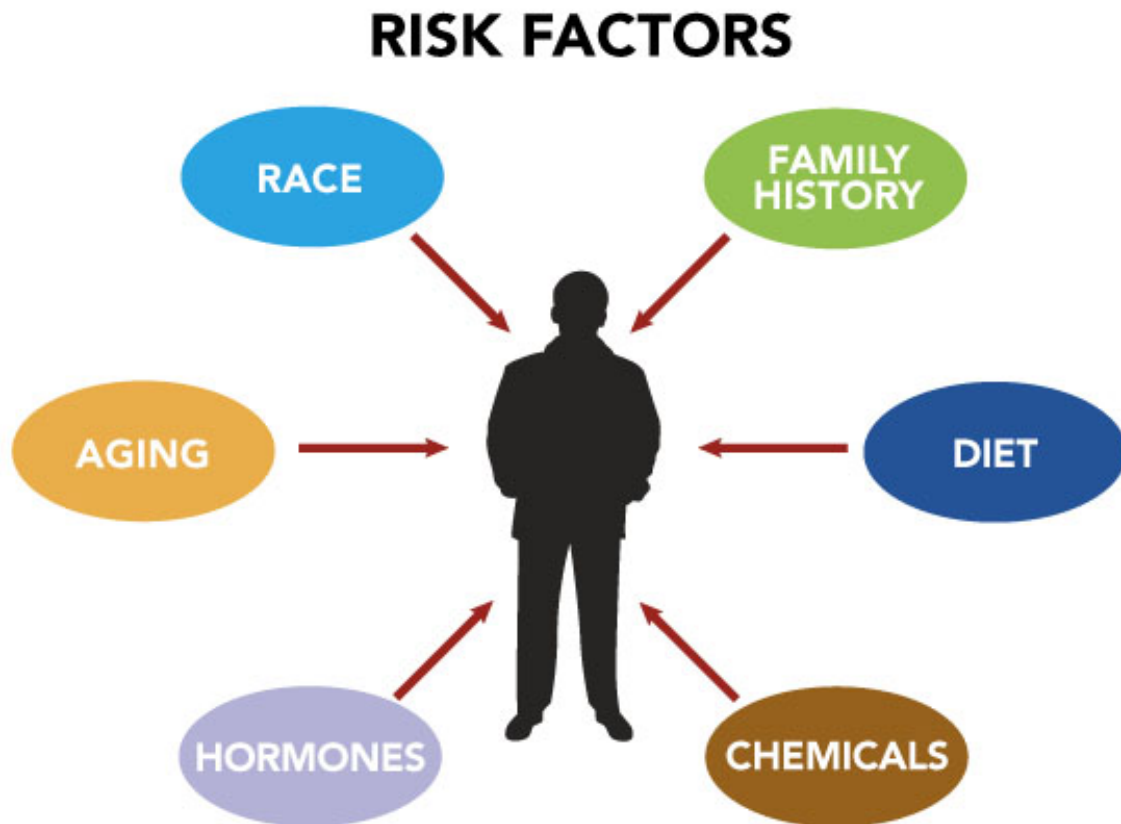
Please watch the video:

<https://youtu.be/CLYEYSDEnVA>

All men are at risk for prostate cancer.

- Out of every 100 American men, about 13 will get prostate cancer during their lifetime, and about 2 to 3 men will die from prostate cancer.
- The most recent research shows that the five-year survival rate for all men with prostate cancer is nearly 100%

| 5 YEAR SURVIVAL RATE |           |       |       |
|----------------------|-----------|-------|-------|
| YEAR RANGE           | ALL RACES | WHITE | BLACK |
| 1975 - 77            | 68%       | 69%   | 61%   |
| 1987 - 89            | 83%       | 84%   | 71%   |
| 2009 - 15            | 99%       | 99%   | 97%   |



[https://www.cdc.gov/cancer/prostate/basic\\_info/risk\\_factors.htm#:~:text=All%20men%20are%20at%20risk%20for%20prostate%20cancer.,cancer.%20The%20most%20common%20risk%20factor%20is%20age.](https://www.cdc.gov/cancer/prostate/basic_info/risk_factors.htm#:~:text=All%20men%20are%20at%20risk%20for%20prostate%20cancer.,cancer.%20The%20most%20common%20risk%20factor%20is%20age.)

### How is Prostate Cancer Diagnosed?

Prostate cancer is diagnosed by using several tests. You might have undergone a few of those tests already. There are many other tests to find out the spread of cancer.

The order of testing is:

1. **PSA test:** The PSA test is a blood test that measures the amount of prostate-specific antigen (PSA) in your blood. PSA is a protein produced by normal as well as cancer cells of the prostate gland.
2. **Digital rectal examination (DRE):** Digital Rectal Examination is done to feel the prostate gland through the rectum walls to check for any lumps or challenging areas and get an idea of the size of the gland.
3. **Prostate biopsy:** In a prostate biopsy, small tissue pieces are taken out with a biopsy needle. The tissues are then looked at under a microscope to check for cancer or other abnormal cells. Cancer can only be diagnosed with a prostate tissue sample.
4. **Transrectal ultrasound:** A small probe (size of a finger) is inserted into the rectum to check the prostate. The probe bounces harmless high-energy sound waves (Ultrasound) off the prostate surface, creating videos or photos of the gland. The transrectal ultrasound is often used during a biopsy procedure. This can provide images of the prostate at different angles and help your doctor estimate the size of your prostate and spot abnormal growths.
5. **MRI scan:** A magnet resonance imaging (MRI) uses magnets to create a detailed picture of your prostate and the surrounding tissues. You may have had an MRI scan to help your doctor decide whether you need a biopsy or decide which prostate areas need biopsies. MRI is also used to see if cancer has spread outside the prostate.
6. **CT scan:** A computerized tomography (CT) scan can show whether cancer has spread outside the prostate, to the lymph nodes or nearby bones.
7. **Bone scan:** A bone scan can show whether any cancer cells have spread to your bones. A small amount of safe, radioactive dye is injected into a vein in your arm before you have

the scan. The dye will collect in the areas in the bones if there is any cancer in the bones and show up on the scan.

- 8. PET scan:** A positron emission tomography (PET) scan shows how well different parts of your bodywork. It can be used to check if cancer has spread outside the prostate.

The goal of advanced testing is to provide you and your health care team with more information to create the best treatment plan for you.

\*\*Download or visit genomic and advanced testing options for prostate cancer for more information\*\*

## Understanding Your Prostate Cancer

Test results will help you get a clearer picture of your prostate cancer. You will want to get familiar with the terms stage, grade, and risk group. All these terms are used to classify your prostate cancer and determine the best treatment options for you. Most prostate cancer grows slowly and may never cause any problems or shorten one's life. So, having prostate cancer does not necessarily mean that you will die from it.

**Stage:** Staging determines if and how far cancer has spread beyond the prostate. There are four stages of prostate cancer: I through IV. You might have an MRI, CT, or bone scan to determine the stage of your cancer. A CT or bone scan is not needed if your PSA is low, and your biopsy results suggest that cancer is unlikely to have spread.

For localized prostate cancer, you may not need treatment, or you could have treatment with the goal of getting rid of cancer. You will have treatment for locally advanced prostate cancer to get rid of cancer or keep the disease under control. The treatment will not cure your cancer for advanced prostate cancer, but you will receive treatment to keep it under control.

| PROSTATE CANCER STAGES |   |
|------------------------|---|
| <b>Stage I</b>         | - the cancer is small and only in the prostate  |
| <b>Stage II</b>        | - the cancer is larger and may be in both lobes of the prostate but is still confined to the prostate   |
| <b>Stage III</b>       | - the cancer has spread beyond the prostate to close by lymph glands or seminal vesicles  |
| <b>Stage IV</b>        | - the cancer has spread to other organs such as the bone and is referred to as metastatic cancer. If prostate cancer spreads, or metastasizes, to the bone, you have prostate cancer cells in the bone, not bone cancer |

For a detailed description of each stage, see the information at the bottom of the page.  
Detailed Staging, adapted from [www.cancer.gov](http://www.cancer.gov).

**Grade:** Your prostate cancer's grade, called a Gleason score, is a good indicator of the aggressiveness of your disease and indicates how likely it is for the tumor to spread from the prostate to other parts of the body. The Gleason score is the addition of two Gleason grades. The first number is the most predominant cell pattern in the biopsy samples, and the second grade is the second most predominant cell pattern. The total of these two grades was added together to determine the Gleason score. Gleason scores range from 2 to 10; the higher the number, the more abnormal the prostate tissue compared to normal tissue, and more cancer are more likely to spread.

| GLEASON SCORES IN CATEGORICAL ORDER |  |
|-------------------------------------|--|
| <b>Gleason X</b>                    | Gleason score cannot be determined   |
| <b>Gleason 6 or less</b>            | The tumor tissue is well differentiated, less aggressive and likely to grow more slowly                              |
| <b>Gleason 7</b>                    | The tumor tissue is moderately differentiated, moderately aggressive and likely to grow but may not spread quickly   |
| <b>Gleason 8-10</b>                 | The tumor tissue is poorly differentiated or undifferentiated highly aggressive and likely to grow faster and spread |

**Risk group:** The risk group provides information about the possibility of cancer coming back or progress. Advanced genomic tests are available to go beyond the standard risk assessment with



the PSA and Gleason score. These tests predict the spread of cancer beyond the prostate, aggressiveness, and the likelihood of disease return.

## Prostate Cancer: Risk Stratification:



### Pretreatment risk stratification for prostate cancer

| Risk group   | Clinical stage   | Gleason score | Serum PSA      |
|--|--|---------------|----------------|
| <b>Standard risk groups</b>  |  |               |                |
| Low-risk   | T1c-T2a  | ≤6            | <10 ng/mL      |
| Intermediate-risk  | T2b  | 7             | 10 to 20 ng/mL |
| High-risk  | T2c  | 8 to 10       | >20 ng/mL      |
| <b>Risk groupings used by Memorial Sloan-Kettering and Seattle groups (1, 2)</b> |  |               |                |
| Low-risk   | ≤T2a   | ≤6            | <10 ng/mL      |
| Intermediate-risk  | One elevated risk factor:<br>Clinical stage ≥T2a disease, Gleason score ≥7,<br>PSA ≥10 ng/mL |               |                |
| High-risk  | Two elevated risk factors  |               |                |

T1c: tumor identified by needle biopsy (eg, because of elevated PSA); T2a: tumor involves one-half of one lobe or less; T2b: tumor involves more than one-half of one lobe but not both lobes; T2c: tumor involving both lobes.

1. Zelefsky, M, et al. *Int J Radiat Oncol Biol Phys* 2000; 47:1261.

2. Blasko, J, et al. *Int J Radiat Oncol Biol Phys* 2000; 48:111.

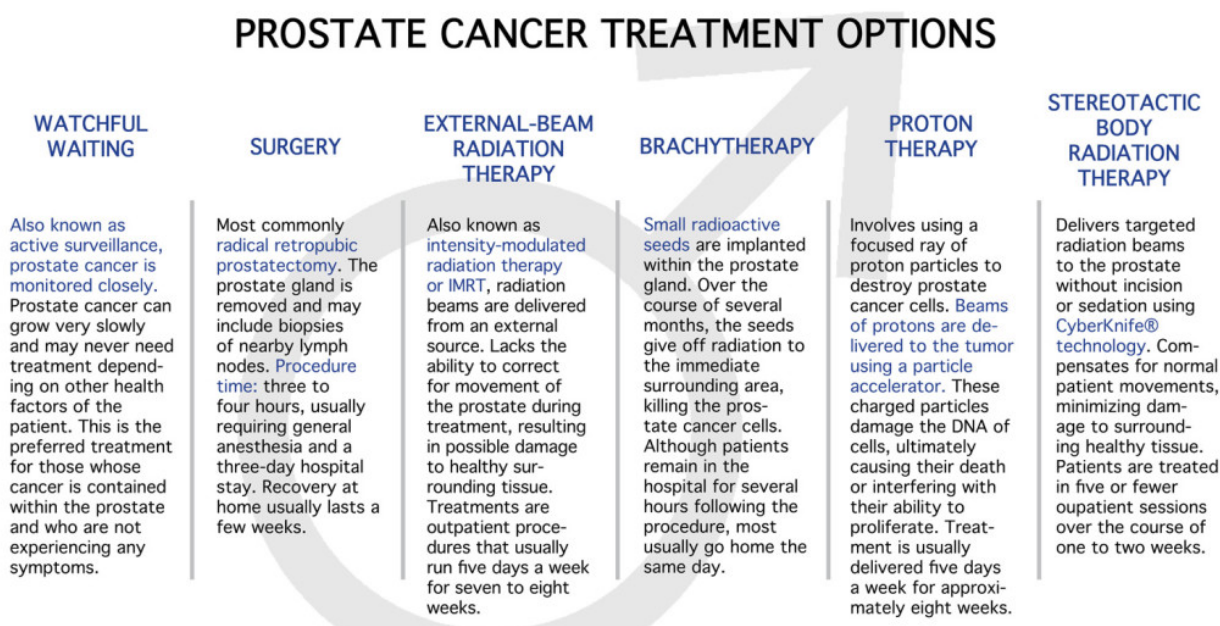
**Treatment options**

Prostate cancer treatment depends on various factors such as the size and location of the tumor, the aggressiveness of cancer, the spread of cancer, and your overall health. Choosing the treatment is a very personal decision depending on your personal needs and preferences. There are many treatment options for men with prostate cancer.

1. **Active surveillance:** Active surveillance is only done with men who would otherwise be ineligible for treatment and requires routine follow-up, exams, labs, and biopsies.
2. **Watchful waiting:** Watchful waiting is simply waiting for symptoms to show up in men with other competing diseases or advanced age.
3. **Surgery:** A prostatectomy removes the prostate gland by surgery to remove all cancer from your body. There are different types of prostatectomies (Open, Laparoscopic, Robotic)
4. **Radiation therapy:** Radiation therapy uses high-energy rays to target the prostate and any surrounding areas with cancer or at the risk of cancer.
5. **Cryotherapy:** Cryotherapy freezes prostate tissues to make cancer cells die.
6. **Hormone therapy - androgen deprivation therapy (ADT):** Prostate cancer is fed by male hormones; this androgen is called testosterone. ADT stops your body from making testosterone to stop or shrink the tumor. Regular testosterone tests to monitor the level of this hormone will help determine if treatment is effective when undergoing hormone therapy.
7. **Chemotherapy:** Chemotherapy is used to kill cancer cells and prevent them from multiplying. Intravenous or oral drugs are used in chemotherapy.

8. **Brachytherapy:** Brachytherapy is implanting a tiny placement of radioactive seeds or temporary needles into the cancerous prostate. Placement of seed is a minimally invasive procedure and does not require incisions. You can return to total activity in less than a week if you undergo brachytherapy.
9. **Immunotherapy:** In immunotherapy, a man's immune cells are used to attack advanced prostate cancer.
10. **Ultrasound:** high intensity focused ultrasound (HIFU) is used to destroy cancer by using sound waves on the prostate tumor.
11. **Androgen Deprivation Therapy (ADT):** ADT or hormone therapy is used to lower androgen levels or stop them from getting into prostate cancer cells. It makes prostate cancers shrink or grow more slowly and is often used in combination with other treatments.
12. **Radium-223:** Radium-223 (Xofigo) is a drug used in advanced prostate cancer: when cancer has spread to their bones after surgery or other treatments. Radium-223 is injected through a vein once a month for a total of six months (6 doses).

Please watch the video to know more about treatment options  
<https://www.youtube.com/watch?v=e6h7BxOZuCU>



(CDC)

You may be able to have treatment to get rid of cancer or may be able to have treatment to keep cancer under control.

### Your Family's Involvement

You might feel worried about sharing about your cancer with friends and family. You might be concerned about their reaction to the diagnosis, or you may think that you will upset them. It could be challenging to start the conversation about cancer, but this booklet may be helpful to share the information and explain the condition. Find a quiet place and quiet time to discuss the diagnosis. Write down all your questions and concerns to ask your doctor or nurse at your next appointment.

**Treatment Side Effects / Expected Outcomes**

There are various expected outcomes and side effects from each treatment for prostate cancer. As prostate cancer varies from person to person, so do the side effects and expected outcomes. Your team will help you to minimize the side effects after treatment.

The most significant expected side-effects include urinary incontinence (leakage of urine/ the inability to control your bladder) and erectile dysfunction. Fatigue, depression, and infertility are other side effects and expected outcomes of prostate cancer treatment. You and your partner need to discuss these potential side effects and expected outcomes and discuss them with your physician before choosing the treatment. These changes could significantly impact your self-esteem and personal relationship. Your health care team will be able to plan for and manage these expected outcomes depending on your choice of treatment.

Watch this video for more information (Managing common side effects of prostate cancer treatment)

<https://youtu.be/CgiTYFLrB1w>

### MANAGING SIDE EFFECTS

| TREATMENT               | WHAT IT DOES   | POSSIBLE SIDE EFFECTS   |
|-------------------------|--|---|
| Surgery                 | Removes the cancerous tissue and the prostate  | Urinary incontinence, erectile dysfunction (ED), and infertility  |
| Hormone Therapy         | Minimizes presence of androgens which fuels prostate cancer growth                     | ED, hot flashes, and bone loss  |
| Radiation               | Slows prostate cancer cell growth by targeting cells externally or by injection        | ED, incontinence, diarrhea, rectal bleeding and discomfort during urination and bowl movement           |
| Immunotherapy           | Changes the body's immune system to kill cancer cells                                  | Fever   |
| Bone-related Treatments | Inhibits bone loss and fractures and relieves pain from prostate cancer in the bone    | Tiredness, diarrhea, nausea, and weakness   |
| Chemotherapy            | Targets cancer cells that grow quickly including cancer cells metastasized to the bone | Hair loss, fragile bones and nervous system disorders like confusion, depression, headaches, and nausea |

(CDC)

### What Do I Do After Treatment?

Monitoring for recurrence is essential after the completion of treatment. Most men will live cancer-free for years. Up to 40% of men will experience a recurrence, so it is vital to understand the risks and continue to monitor for the return of cancer by regular PSA testing. The biochemical recurrence is the rise in PSA to a certain threshold after prostate cancer treatment. It shows that some cancer cells have survived and are producing PSA after treatment. Your doctor

will order additional tests and make further treatment recommendations to manage if this does occur.

### **Prostate Cancer: A Family Disease**

Your prostate cancer diagnosis affects you and your entire family. It is essential to have your support system to help you cope with the diagnosis emotionally and physically and help you decide which treatment is proper for you. It is imperative to discuss the diagnosis and your values and preferences with your family and friends. Bring your partner for the follow-up appointment to decide treatment or bring a close friend if you do not have a family member or a partner.

If you have brothers, sons, or other male friends, you may want to talk to them about their own risk of prostate cancer. It is imperative to inform your children, grandchildren, and extended family about your diagnosis and the need for an early prostate cancer screening process, mainly if they are 45 years or over. Men have two and a half times more likely to get the disease if their father or brother had prostate cancer since it is a hereditary disease.

### **Coping by Yourself**

Everyone has their way of dealing with illnesses, especially prostate cancer. Find out the different treatment options you could have after reading the information in this booklet. Clarify all possible side effects to know what to expect and manage them to make the decision that's right for you.

Talk to someone close to you or someone trained to listen, like a counselor, doctor, or nurse. Set up some goals for yourself and plan things according to your interests to look forward to fulfilling them. Take some time for yourself by learning some breathing exercises and listening

to soothing music to manage your stress and relax. Keep yourself active to improve your physical strength and fitness and lift your mood and positive spirit.

Eat well to stay healthy and keep your general health in good condition to feel more under control and cope with the treatment.

Please visit this website for more information

<https://prostatecanceruk.org/prostate-information/living-with-prostate-cancer/your-diet-and-physical-activity>

### **Additional Support**

Feeling frightened, isolated, or angry are common when you hear the diagnosis of prostate cancer. Please write down all your questions and concerns, and do not be afraid to speak up and ask for help with the decision-making of treatment or aftercare. Your health care team and support groups will help you throughout this journey.

Your medical team can explain your diagnosis, treatment options, and side effects; they will listen to your concerns and connect with others who can help you. The specialist nurse will take time to listen to any concerns you, your family, your friends, or people close to you may have about the diagnosis.

You may also consider thinking about spiritual beliefs due to having prostate cancer. You could get spiritual support from your family, religious leaders, or faith group to help you cope with the diagnosis and treatment with a better outcome.



