
Advanced Clinical Practice

Shared Decision Making in Patients With Newly Diagnosed Prostate Cancer: A Model for Treatment Education and Support

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Prostate cancer is the second most prevalent cancer among American men and is the second leading cause of cancer deaths. Estimates of incidence range from 1 in 11 to 1 in 5 men who will be diagnosed with prostate cancer at some point in their lives. Approximately 220,900 new cases were diagnosed in 2003, with an estimated 28,900 deaths (American Cancer Society, 2003). Prostate cancer is a disease that usually affects men age 50 and older. African-American men have the highest incidence of prostate cancer in the world. These men are more likely to be diagnosed at later stages of the disease and have a higher death rate from prostate cancer than Caucasian men (Centers for Disease Control and Prevention [CDC], 2003).

A new diagnosis of any illness may provoke feelings of uncertainty and anxiety. A diagnosis of cancer carries with it a particular sense of dread and may magnify those feelings. An individual with a new diagnosis

Screening for prostate cancer is controversial. Treatment choices for verified cases of prostate cancer provide another level of controversy as to which treatment, if any, is best. This controversy and uncertainty create a dilemma for the newly diagnosed patient. A great deal of information must be assimilated if the patient is to make an informed decision to pursue any treatment. A metropolitan Veterans Affairs hospital has created a model to assist the newly diagnosed prostate cancer patient in acquiring this information, while helping him through the decision tree. This model, which utilizes the skills of the advanced practice nurse, strives toward maintaining the patient's autonomy while clarifying these uncertainties, introduces the concept of shared decision making, and provides a potential support group.

of cancer is likely to feel frightened, confused, anxious, and/or vulnerable. Prostate cancer is no different in eliciting such tumultuous emotions. In fact, the controversy over the efficacy, and even necessity, of prostate cancer screening and treatment only adds to the patient's dilemma of uncertainty (Woolf & Rothemich, 1999).

Uncertainty as a conceptual component of illness has been studied (McCormick, 2002). The shock of a newly diagnosed illness may leave the patient in a cognitive state in which the value, meaning, or outcome of a particular event cannot be perceived or predicted. This uncertain state can leave the decision maker, in this case the patient, in an ambiguous fugue (Mishel, 1988) in which he finds it difficult to discern any clear path towards health. The patient's thinking may be clouded by the

fact that he is now a "victim" of a disease state.

Probability, temporality, and perception are all attributes of uncertainty in a disease state (Morse, 2000). Probability refers to the likelihood of something happening. Temporality refers to duration, pace, and frequency of the condition. Perception refers to the individual's impression or interpretation of the given situation. For example, the patient, upon hearing of his diagnosis, may be thinking: What are my chances of survival? (probability), How long do I have? (temporality), and What does this all mean? (perception). A high level of uncertainty is positively correlated to a high level of emotional stress. However, uncertainty can be "a door to hope, an opportunity to challenge," not just a threat (Babrow, Kasch, & Ford, 1998, p. 9). The basic way of opening that door for opportunity is to pro-

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vide the information that the patient is lacking. This information gives the patient a frame of reference, which begins to dispel the uncertainty (Maliski, Heilemann, & McCorkle, 2002; McCormick, 2002).

Educating the patient and spouse, or other family members, about prostate cancer facts/treatments becomes of paramount importance. Much of the prostate cancer information obtained is from nonmedical sources, such as family, friends, and lay literature (O'Rourke & Germino, 1998). This can result in many conflicting opinions and misinformation, may increase the patient's uncertainty, become a barrier in the decision-making process, and can delay treatment altogether.

Review of Literature

Sources of uncertainty. There is lack of clinical consensus on which treatment, if any, is best for prostate cancer. Treatment choices are used either singularly or in combination and are selected after patient consultation with the physician. According to the CDC (2000), radical prostatectomy is chosen by at least 58% of the patients. Other choices include radiation by external beam (36%), medical castration with luteinizing hormone-releasing hormone agonists (20% to 30%), hormonal ablation by orchiectomy (12%), and brachytherapy (6%). Nine percent of patients choose watchful waiting with surveillance of the PSA and DRE every 6 to 12 months. Other treatments include cryotherapy at 4% and complementary and alternative medicine at 42% (Wilkinson et al., 2002). Chemotherapy is used in cases of widely metastatic disease.

Of the treatment modalities listed above, radical prostatectomy and radiation therapy are the two most widely used options as well as the two most aggressive approaches to the disease. The majority of urologists and patients prefer an aggressive approach, despite research that has questioned the overall effectiveness of treatment (Crawford et al., 1997). A Scandinavian

study in 2002 compared mortality rates between radical prostatectomy and watchful waiting. The results showed that overall survival was not significantly different between the two groups (Holmberg et al., 2002).

The Scandinavian study, however, did not examine quality of life differences, which involves another factor to confound treatment decisions. Urinary incontinence, erectile dysfunction, urinary obstruction, cystitis, hot flashes, decreased libido, proctitis, and lethargy are the more common treatment sequelae (Siston et al., 2003). Percentages of these side effects vary greatly in the literature (Burack & Wood, 1999; Walsh, 2002).

Even with watchful waiting, sexual dysfunction, obstructive voiding, and fecal incontinence are also possible quality of life issues, presumably from disease progression (Holmberg et al., 2000). If the disease becomes widely metastatic, then the high probability of pain could be added to the list. Thus, there are no quick and easy guidelines for the patient considering quality of life issues with prostate cancer treatment options.

Significance to nursing. The science and art of nursing embodies a holistic approach to patient care. Addressing the patient's emotional state and teaching patient/family effectively are both vital components of such an approach. Consider the increased clinical knowledge and skills of an advanced practice nurse (APN), and she/he becomes a logical provider for the newly diagnosed prostate cancer patient. As a well-educated health professional, the APN may be board certified in urology, and can usually answer most of the patient's questions. The patient may also consider the nurse less threatening and more of an advocate, since advocacy has always been an integral part of nursing (Foley, Minick, & Kee, 2002). The patient may feel more comfortable in asking questions without any perceived jeopardy of the

doctor-patient relationship. Still, the APN is a member of the health care team and openly communicates and collaborates with the physician. In a teaching institution, where the physicians' rotation time may be limited to a few months, the APN provides continuity of care for the patients as one of the consistent members of the team.

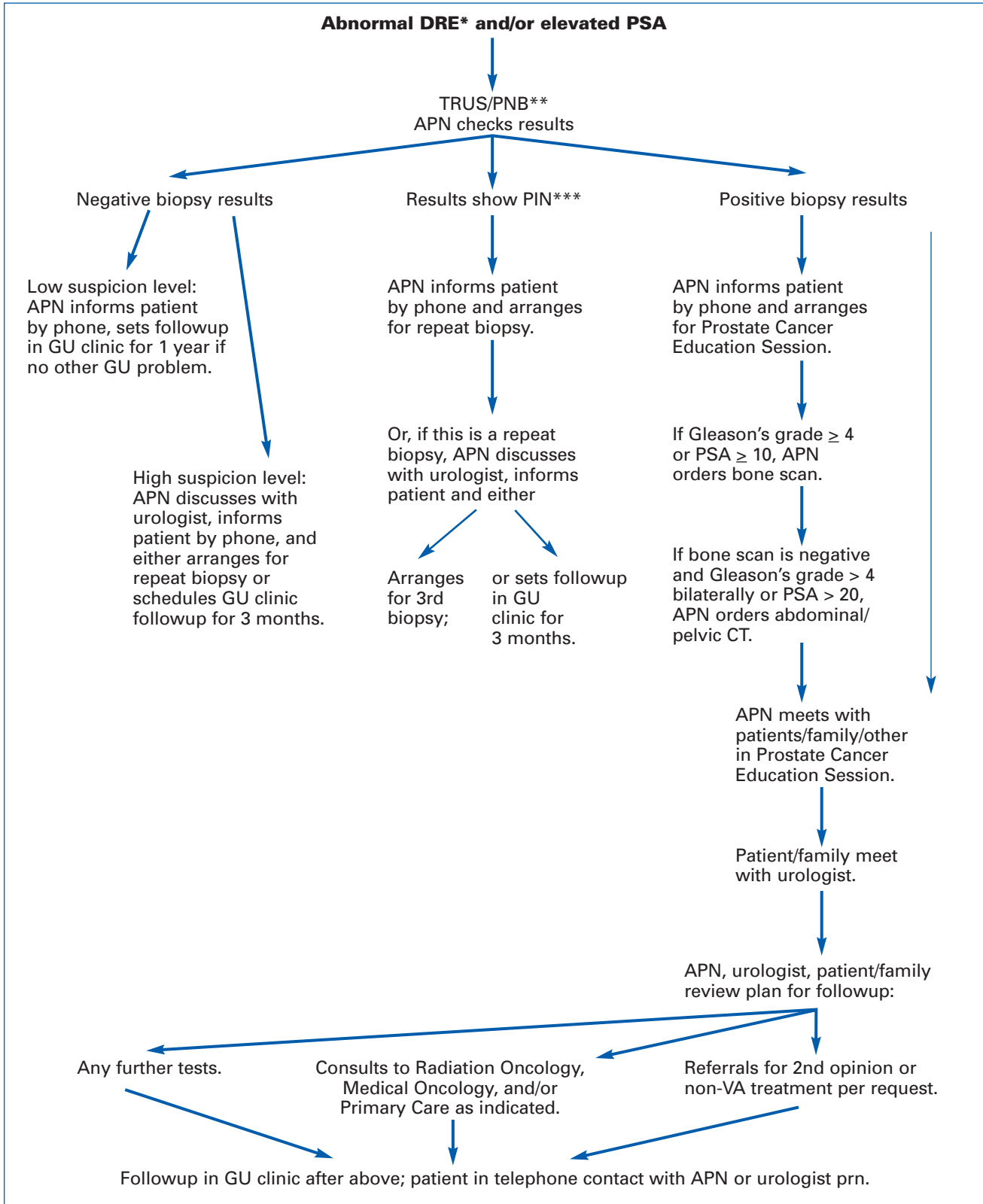
Purpose

The purpose of this article is to outline and discuss a model for providing the needed health information to prostate cancer patients and family in a productive, supportive manner. This model has been used at the Lakeside Division of the Veterans Affairs (VA) Chicago Health Care System since 1997 and serves as the foundation for a triad partnership which includes the APN, the patient, and the physician. Through the use of a *Prostate Cancer Education Session*, an effective tailored intervention has been established to foster shared decision making.

Prostate Cancer Education Session

Patients with confirmed adenocarcinoma, through positive prostate biopsies, are invited, along with their spouses and/or significant others, to attend the Prostate Cancer Education Session. This session is led by the APN and is scheduled prior to the patient having an initial visit with the physician. A clinical strategy algorithm may be used along with the model for the Prostate Cancer Education Session (see Figure 1). This algorithm was developed by the author in collaboration with the urology service. It provides a clear picture of how the patient arrives at the session, outlines sequential steps in the process, and assists in reducing duplication of clinic visits. The VA uses computerized charting, so the laboratory, pathology, and examination reports are readily available to the APN. Some of the specific numeric guidelines, such as prostate-specific antigen level

**Figure 1.
The Strategy Algorithm**



* DRE = Digital rectal examination

** TRUS/PNB = Transrectal ultrasound/prostate needle biopsy

*** PIN (prostate intraepithelial neoplasia is dysplasia that frequently is a precursor of prostate cancer.

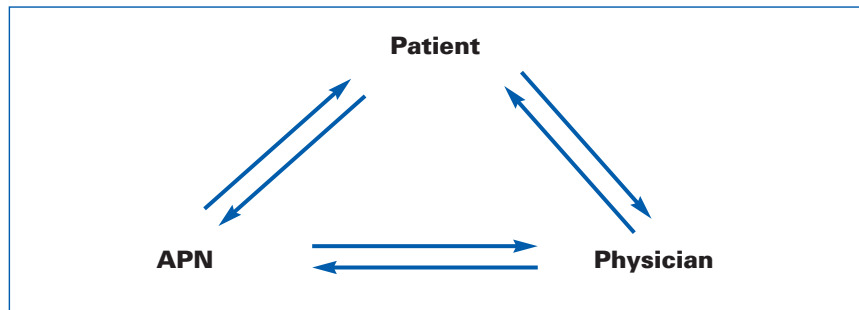
that might dictate the need for a bone scan, may vary from practice to practice.

The APN usually works with a small group of patients/spouses or significant others, instead of one-on-one. When the patient sees the physician, the patient and spouse already have a basic knowledge of the treatment options for prostate cancer and may have already formed an opinion. The physician then offers a brief review, answers any additional questions the patient/spouse may have, inquires as to the patient's preferences, and makes recommendation(s).

Positive group dynamics allow the Prostate Cancer Education Session to act as a support group. The benefits of cancer support groups are well documented (Klemm, Reppert, & Visich, 1998). The assistance people seek include factual information, opinions, encouragement, shared experiences, and the psychological support so important for anyone with a diagnosis of cancer. Meeting people who are battling the same situation relieves a sense of aloneness and helps develop coping skills. This connection with others may lead to a restorative wholeness of mind, body, and spirit that may be just as important as the most cutting-edge advances in cancer treatment (Johnson, 2000). The group dynamic benefit extends to the spouse as well. Support group experiences reduce spousal stress and uplift her mood, which positively affect the patient's coping (Manne, Pape, Taylor, & Dougherty, 1999).

In the 5-year history of the Prostate Cancer Education Session at the VA, patients and their spouses have "connected" to the group in varying degrees. By the end of the session, they frequently are sharing telephone numbers, joking, and showing concern for each other. This is an especially good outcome since research has shown that majority of men (87%) will not reach out toward support groups on their own, even though those who do report a higher health-related quality of life (Katz et al., 2002).

Figure 2.
The Triad Partnership



Whether or not the group at the Prostate Cancer Education Session connects, the APN provides additional information about other formally organized prostate cancer support groups (Man-to-Man, US TOO), and lends encouragement for participation.

The Model

The model, which lays the foundation for this approach, delineates a triad partnership. The APN is the main facilitator/expert educator/primary information source. The APN provides general knowledge about the disease and its treatments. The patient is the main recipient/personal information provider/primary decision maker. He provides specific knowledge about his own illness, his salient beliefs, expectations of treatment, and personal values of side effects or outcomes of treatment. The physician is the main advisor/treatment specialist/secondary information source. Through a second opinion or consultation, there may be more than one physician involved.

This model, leading toward shared decision making, involves sequential interactions. It begins with the APN-patient encounter, which leads to the physician-patient encounter, and then the APN-patient-physician encounter. The model, however, is multidirectional, creating an open dialogue among patient, APN, and physician(s) (see Figure 2). The end result is the formation of a therapeutic alliance.

Strategy for Change: Shared Decision Making

The ambiguity of any one clear course for prostate cancer treatment truly lends itself to shared decision making. According to Snyder (1999), shared decision making is a manner of communication between clinician and patient, which is based upon the broad context of their relationship in a health care situation. It is an approach that requires input from both and ultimately leads to a mutually agreed upon plan tailored to maximize the patient's health (Wei & Uzzo, 2002). It respects the patient's autonomy while utilizing the clinician's expertise.

Shared decision making rejects the paternalistic role of the clinician, but falls short of a mandatory autonomy model (Ubel, 2002) or consumerism model (Deber, 1994a) for the patient. It encompasses informed consent but moves beyond, toward a partnership in which the patient's values and preferences are considered (Snyder, 1999). Decision making requires problem solving, but is not to be confused with it (Deber, Kraetschmer, & Irvine, 1996). The clinician may offer and explain the solutions to a problem (for example, treatments for prostate cancer) but it is the patient and clinician together who make the decision for the plan of care based upon the patient's preferences. So ultimately, it is the patient who finalizes the decision, with guidance from the clinician's input.



Communicate effectively. Because patients have different preferences and barriers to learning, it is best to use a multi-media approach for teaching.

Patients want to be involved in the decision-making process. According to Deber et al., (1996), 98% of those surveyed wished the problem-solving tasks would be performed or shared with the physician, and 78% wished to be involved in decision making. However, the desire for involvement is lessened if the patient is older, sicker, not highly educated, or has a spouse (Deber, 1994b; O'Dell, Volk, Cass, & Spann, 1999).

There is ambiguity in cases where patients are reluctant in making a decision. Still, the clinician must solicit the patient's preferences accurately before making a recommendation. The potential problem is that physicians may be poor judges of their patients' wishes. The physicians' description of patient encounters and their judgments of quality of life health states associated with prostate cancer may differ greatly from the patients' (Chan & Sulmasy, 1998; Deber, 1994b; Knight et al., 2002).

The Prostate Cancer Education Session is ideal for this reluctant, uncertain patient. It presents the opportunity for the APN to use the model for treatment education and to gently guide the patient toward shared decision making. The APN presents all the information in a relaxed, non-threatening, nonpressured manner. The concept of shared decision making and its rationale is specifically addressed at the session, allowing the patient more time for consideration.

Maximizing the Strategy

The most time-consuming component of successful shared decision making is ensuring that the patient has received and assimilated all the necessary information to make an informed shared decision. There is a great deal of information to relay concerning prostate cancer and its treatments. Having a separate clinic time devoted to this purpose allows more time to accomplish this task so the patient is educated rather than simply informed. Information giving is a

traditional approach to patient education. Today's system of health care delivery focuses on limited and ever-shorter inpatient stays, quick turnover times, and more outpatient and home management of medical problems. Because of this focus, the patient needs to be educated in a self-management approach (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Therefore, education is patient centered, which includes and leads to shared decision making.

To maximize the Prostate Cancer Education Session, the clinician should incorporate effective techniques of patient health education. These techniques include (a) establishing rapport, (b) exploring concerns, (c) communicating effectively, and (d) assisting the patient to action. Such techniques honor the patient as a partner in the decision-making process (Pries et al., 2003).

Establish rapport. A basic but primary first step is to establish rapport with the patient(s). A friendly greeting, clearly identifying yourself, and offering interested/positive comments about the patient are all good verbal attending skills. Smiling, offering a handshake, making eye contact, sitting at the same level (for example, sitting around a conference table versus a classroom setting) are all good nonverbal attending skills. These basic attending skills lay the groundwork for establishing an effective relationship. Patients are also introduced to each other to establish inter-group rapport. Listening attentively builds rapport and is crucial to encourage each patient's and family member's participation. Good listening helps to obtain information. This skill aids the listener to identify and reflect any emotional component, assess any particular voiced needs, and ultimately

evaluate comprehension (Pries et al., 2003; Snyder, 1992).

Explore concerns and preferences. This can be done throughout the session, but initially, the clinician may ask each patient to write down or state what comes to mind when he hears the words "prostate cancer." Most people have approximately seven thoughts or ideas about any given topic. These salient beliefs, according to the Salient Belief Model, may reflect attitudes, emotions, and values, which are so important in the decision-making process (Lorig, 2001). The beliefs may then be supported or refuted at appropriate times during the discussion. Much of the session will have to do with cognitive input. The patient needs facts about prostate cancer, but also needs to have any myths dispelled. It may be helpful, and time efficient, if each patient completes a needs assessment sheet of prostate cancer topics at the end of the session (Pries et al., 2003) (see Figure 3). The patient can refer to the assessment sheet during the physician visit to focus further discussion. Patients with low-literacy skills may need reinforcement in the use of this needs assessment list as written lists may be difficult for them to decipher (Doak, Doak, & Root, 1996).

Communicate effectively. Because patients have different preferences and barriers to learning, it is best to use a multi-media approach for teaching. The Prostate Cancer Education Session incorporates lecture/discussion, booklets and pamphlets, videotapes, and question-and-answer opportunities as helpful decision aids (O'Connor et al., 1999). Each patient is handed a folder containing pertinent booklets/pamphlets with his name written on the folder. This little act of personalizing translates to better adherence to reading the

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Figure 3.
Needs Assessment Checklist

Name _____

PROSTATE CANCER

"I'm interested in or would like to know more about..."

Place an X before each topic you are interested in or would like to have more information about:

TOPIC

___ 1. PSA (prostate-specific antigen)

___ 2. Gleason's grade

___ 3. Prostate gland

___ 4. Surgery – removal of the prostate (radical prostatectomy)

___ 5. Radiation therapy – external beam

___ 6. Brachytherapy – radioactive seeds

___ 7. Watchful waiting

___ 8. Hormonal therapy – Injection(s)

___ 9. Removal of testicles (orchiectomy)

___ 10. Bone scan – CT scan

___ 11. Urinary leakage

___ 12. Impotence – erectile dysfunction

___ 13. Diet

___ 14. Other questions: _____

Adapted with permission from Pries et al. (2003).

Shared Decision Making

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contents of the folder (Snyder, 1992). The folder also contains support group literature as well as the clinician's card, so the patient has a contact number.

The materials of the folder are reviewed with the patients. Some of the booklets' pictures/explanations are used in the lecture/discussion. This is generally a small group of people convened around a conference table. Videotapes, selected for their educational quality, are either shown in their entirety or in pertinent small clips. Question-and-answer sessions follow each video to clarify information and to assess comprehension. Material covered includes prostate cancer information, expla-

nation of staging the illness, any additional tests that may be needed, treatments, and side effects. All treatments are discussed, whether or not they are available in the VA system.

Assist the patient to action. At this point, the clinician emphasizes that patients are not expected to "act" or make a decision. Most patients at this phase are in Contemplation Stage of the Stages of Change (Prochaska & DiClemente, 1982). As each patient has a great deal of information to consider, the APN can answer any further questions, refer him to the additional listed resources in his folder, and arrange for him to see the urologist. At the end of that meeting, the urologist, APN, and patient/family briefly review the followup plans.

These plans include scheduling any further tests, consultations to medical or radiation oncology, and/or consultations to primary care for preoperative consideration. Referral for treatments not available at the VA may be available upon request. Once the above consults/tests have been completed, a return appointment to the urology clinic is scheduled to discuss the patient's treatment decision and to ensure continuity of care. The patient/family is encouraged to call the APN or urologist if any further questions develop in the interim.

Conclusion

Shared decision making can improve health outcomes, increase patient and clinician satisfaction, increase patient adherence to treatments, decrease malpractice litigation, and use health care resources more effectively (Flood et al., 1996; Snyder, 1999).

The Prostate Cancer Education Session provides an effective tailored intervention (Ryan & Lauver, 2002) that lays the groundwork for successful shared decision making. In our experience, it generates high patient, physician, and nurse satisfaction; is efficient use of time; and has potential for support group dynamics. Advantages to this education session, in addition to comfort level of patient and continuity of care already mentioned, are time efficiency and positive group dynamics. The APN can spend more quality educational time with the patient/spouse by offering a group educational session.

The possibility for research of this approach exists. Qualitative studies exploring effects on uncertainty, anxiety, or vulnerability of the patient, patient and/or clinician satisfaction, effects of shared decision making, or educational outcomes of the session are some plausible examples. This approach may be improved if all involved specialties were invited to attend the session to present their information personally, rather than just the surgeon. ■

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