

The Center for Prostate Care, ProHealth Care Regional Cancer Center, Wisconsin

A prostate care coordinator supports, educates, and guides patients through diagnosis, treatment, and follow-up BY DON JEWLER

The Center for Prostate Care in Waukesha, Wisconsin, is dedicated to treating men with prostate and other urological and genital cancers. Two programmatic elements set the center apart from its competitors. First, every patient's care is coordinated and administered in one facility by a multidisciplinary team of specialists. Second, a care coordinator makes the journey easier by guiding patients through all aspects of diagnosis and treatment.

Located at ProHealth Care Regional Cancer Center, Waukesha Memorial Hospital, the Center for Prostate Care serves prostate cancer patients from Waukesha County and all of southern Wisconsin. It offers urologic surgery, medical oncology services, and radiation oncology services, including brachytherapy, intensity-modulated radiation therapy (IMRT), and CyberKnife®. The Center for Prostate Care was one of the first sites in Wisconsin to offer the da Vinci® Surgical System for robotic prostatectomy.

Patients have access to clinical research specific to prostate cancer. In fact, the Regional Cancer Center was recognized by the Commission on Cancer in 2007 as one of the most successful community-based oncology clinical research programs in the country for enrolling a record number of patients in cancer clinical and prevention trials.

Free screenings are offered all year round through the Center for Prostate Care. In addition, screenings are held at all three of the Regional Cancer Center locations, which are geographically distributed in Waukesha County. Following American Cancer Society guidelines, screenings are available to men age 50 and older

(or age 45 and older if African American or with a family history of prostate cancer).

A Dedicated Care Coordinator Trained in Mental Health Counseling

A core philosophy of the Center for Prostate Care is that patients should be empowered with information and knowledge. Most patients will meet with the care coordinator who provides support and education, and acts as a guide through diagnosis and treatment.

"Not all men understand their diagnosis and all of their treatment options," said prostate care coordinator Craig Gordon, RN. "Yet knowing your options is key to making the best treatment choice. That's why we're committed to educating men upfront about prostate cancer and the treatment options available. As a result, they and their families feel more comfortable and ready to make informed decisions."

Gordon is there for patients throughout the navigation process from initial diagnosis to treatment and follow-up contacts—two-week follow-up, six-month follow-up, and at one year. All along the way he provides education and emotional support.

A background in mental health and counseling helps Craig identify his patients' existing stressors and coping skills and assess the potential for developing new skills. At his first meeting, he administers a Distress Tool to

Prostate care coordinator Craig Gordon, RN (left), Waukesha Memorial Hospital (right)



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Waukesha, Wisconsin

each patient, who rates financial, family, job, and health stressors on a 1-10 scale (see page 43). Following the consultation with the prostate care coordinator, the Distress Tool is readministered to evaluate the effectiveness of stress-level reduction. The goal: a two-point drop, at minimum.

To help patients in the treatment-decision process, Gordon provides each man with a four-page sheet that describes prostate gland functions, defines signs and symptoms of prostate cancer and how it is diagnosed, and explains Gleason scoring and staging. He thoroughly explains a visual representation of each treatment. First, second, third, and even fourth-line treatments are arranged by columns that detail side effects and percent likelihood (high, moderate, or low risk) of developing that side effect.

"I do not tell patients what they should do. I want each patient to walk out feeling he was well informed by someone on his side who is unbiased and his support person," said Gordon. "Patients should be of peace of mind with their decision."

Gordon has developed a simple tool to help patients make their treatment decision (see pages 44-47). He lists seven pros and seven cons of each treatment option and has patients rate their concerns. "Instead of just talking, the exercise forces everybody to put a quantitative weight on each treatment option," he said. For men torn between two treatment choices, this rating system can help them decide.

Gordon also leads the monthly prostate cancer support group. As support group facilitator, he has met with 80 percent of the men before they start the group, and developed a rapport that helps lessen their discomfort or anxiety.

The prostate care coordinator is responsible for more than education and providing emotional support. As patient navigator, he is available at multiple points in the treatment process to assist with appointments and procedures. For example, a prostatectomy patient also receives assistance with scheduling imaging tests (bone scans and CTs), the one-day inpatient visit, and the cystogram appointment one week post op. External beam radiation therapy patients receive assistance with imaging test scheduling and at least two visits at the time of their treatments. Gordon helps prostate seed implant patients with imaging test scheduling, a volume study visit, and a day of surgery procedure visit.

Gordon is active in ProHealth Care's Prostate Cancer Second Opinion service, where he coordinates the appointment with the patient, urologist, and radiation oncologist, as well as himself, on one visit. He also acts as a community speaker and fields all community calls.

A Multidisciplinary Team Approach

ProHealth Care's multidisciplinary team, which includes the prostate care coordinator, meets weekly to discuss

individual cases and carefully consider the best treatment options for each patient. These weekly multidisciplinary conferences foster communication among the team and provide a second, third, and even fourth opinion that represent a variety of critical specialties. Results of the conference are shared with all participating physicians as well as the primary care physician.

Most patients receive an individual meeting with the radiation oncologist along with their urologist. All the community medical oncologists are invited to participate in the weekly multidisciplinary conferences. Before each conference, the prostate care coordinator enters Gleason score, medical history, PSA, and past surgeries on the conference template and distributes these to each participant.

Engaging the community urologists to refer patients and to take part in the conferences was "challenging," according to Gordon. His counseling background helped. Craig's challenge was to instill a sense of trust that his role was to provide education, not steer patients one way or another. "It took a couple of years until they had a comfort level high enough to refer patients." The community urologists (primarily two group practices) now frequently refer their prostate cancer patients to the Center for Prostate Care to meet with the care coordinator, and the urologists more frequently take part in the team conference, depending on their schedule and availability.

A multidisciplinary Prostate Steering Committee meets quarterly to discuss continuous improvement of program services. Committee members include the:

- Radiation oncology medical director
- Prostate Center associate medical director (a urologist)
- Regional Cancer Center medical directors (a pathologist and a medical oncologist)
- Prostate care coordinator
- Regional Cancer Center executive director
- Outreach and education coordinator
- Marketing coordinator.

The committee's key recommendations are brought to the Regional Cancer Center Medical Director Meeting to be discussed and then reviewed at the Cancer Committee.

The case studies presented on pages 42 show how two patients have benefited from the Center for Prostate Care. 📖

Don Jewler is senior editor at the Association of Community Cancer Centers in Rockville, Md.

The Center for Prostate Care: Two Real-world Case Studies

Case 1

This 66-year-old patient was vacationing in Florida where his wife suggested they attend a free health screening. The patient agreed and chose a prostate cancer screening, which consisted of a DRE and a PSA blood test. The patient's rectal exam was normal, but his PSA test came back elevated at 4.33. When they came back to Wisconsin, he followed up with his primary care physician and was referred to a urologist, who recommended a prostate ultrasound with biopsy procedure. The patient's biopsy results came back positive for prostate cancer, which was found bilaterally with a Gleason score of 4+3=7.

The patient had heard positive comments about the Center for Prostate Care at Waukesha Memorial Hospital, so he called for a second opinion. The prostate care coordinator scheduled an appointment at the center with a urologist and a radiation oncologist. The prostate care coordinator would also meet with the patient. All records were obtained prior to the appointment so the medical team could review them. This multidisciplinary approach is very effective for the patient and the medical team, because it allows the patient to be seen at one visit with multiple doctors and with the care coordinator, who can provide education and emotional support.

A distress tool was administered to establish the patient's current stress level and determine the need for education about coping skill development. The prostate care coordinator determined that the patient was coping well and had positive support mechanisms already established. Later that same week the patient's case was discussed at the multidisciplinary GU cancer conference, providing the opportunity for multiple physicians to review the case and provide treatment recommendations.

The patient decided on CyberKnife® treatment for his prostate cancer and the prostate care coordinator scheduled him for fiducial placement. The procedure was performed in the Center for Prostate Care with the urologist, radiation oncologist, and prostate care coordinator in attendance. A week later the patient had a CT scan and MRI scan, which would provide the imaging needed to develop a treatment plan for his CyberKnife treatment. A week later the patient began his treatment, which included five total treatments lasting approximately one hour each.

The patient tolerated the treatment well and has become a mentor to other men who are interested in choosing CyberKnife treatment for their prostate cancer. Through the entire process the patient was contacted by the prostate care coordinator at multiple intervals to answer any questions and to provide ongoing emotional support. The prostate care coordinator continued to provide ongoing follow-up with phone calls at six-months and one-year post-treatment.



Case 2

This 61-year-old patient was referred to the Center for Prostate Care by his urologist who scheduled a prostate ultrasound and biopsy procedure due to an elevated PSA level of 4.19. The patient's biopsy result came back positive for prostate cancer, which was found, bilaterally with a Gleason score of 3+4=7.

The patient was then referred by his urologist to the Center for Prostate Care for consultation. The urologist and prostate care coordinator attended this consultation. At the start of the consult, the patient was administered the Distress Tool, which demonstrated a high level of anxiety and stress, level 8 on a scale of 0-10. The patient said that most of his stress was due to fear of the unknown and that he would have difficulty making a decision about a treatment option.

The prostate care coordinator then provided extensive education about prostate cancer and the different treatment options as well as emotional support to help reduce his anxiety level. The patient was also given educational materials, including pamphlets, stress management techniques, a healthy prostate cancer diet, details about the mentor program, and prostate cancer support group information.

The prostate care coordinator helped the patient complete the Decision-making Tool (pages 44-47) designed to help the patient choose a treatment option. It allowed the patient to place a weight value on the different pros and cons of each treatment by selecting a number between 0-10 for each. The tool demonstrated that the patient had a strong interest in robotic-assisted prostatectomy surgery. When the patient was again evaluated post-consultation, his stress level had been reduced to a level 2.

The patient was very interested in attending the prostate cancer support group, which was being held that same evening at Waukesha Memorial Hospital. He heard from other men who had been through different types of treatment and how they coped, and also what had benefited them with their stress when they were diagnosed. The patient found the education and emotional support provided that day was beneficial and aided in making his treatment decision.

The prostate care coordinator scheduled the patient to see a radiation oncologist to further enhance his understanding of all his treatment options. After meeting with the urologist, radiation oncologist, and prostate care coordinator, the patient selected robotic-assisted prostatectomy surgery. The prostate care coordinator continued to follow up with the patient on an ongoing basis in the hospital and with follow-up phone calls. The patient continues to be an active member of the prostate cancer mentor program and support group.

Distress Measurement Tool

Has Any of the Following Been a Recent Cause of Distress?

Please check all that apply:

Practical

- Housing
- Insurance
- Work and/or school
- Transportation
- Childcare
- Finances
- Care for another adult

Emotional Concerns

- Worry
- Fears
- Sadness
- Nervousness
- Adjusting to my illness
- Guilt
- Loss of interest in things

Spiritual and Religious Concerns

- Relating to God
- Loss of faith
- Death and dying
- Meaning of life
- Prayer life

Physical Problems

- Pain
- Nausea
- Fatigue
- Sleep
- Getting around
- Skin itch and/or rash
- Breathing
- Mouth sores
- Eating
- Constipation
- Diarrhea
- Changes in urination
- Fevers and/or chills
- Tingling in hands and/or feet
- Feeling swollen
- Sexual concerns
- Trouble remembering things

Information Needed

- About my diagnosis
- About my treatment
- About complementary therapies
- About diet
- About communication with my:
 - Partner
 - Children

How can we help you? _____

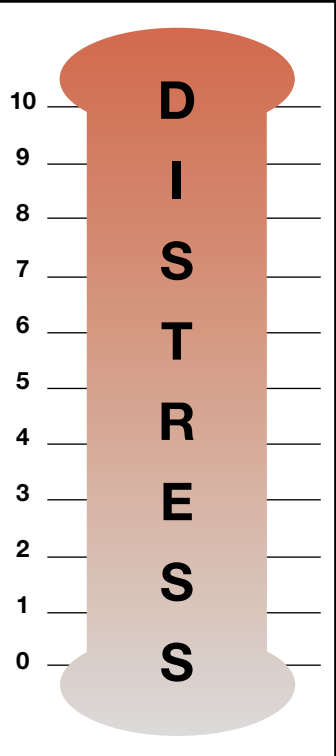
Name: _____

Date: _____

Please return this questionnaire to the nurse you see today. Completion is voluntary and confidential.

Circle the Number that Describes Your Level of Distress*

Extreme distress



No distress

*Distress Level—your level of anxiety, stress, sorrow, or suffering



The Center for Prostate Care Decision-making Tool

This survey is to help you sort through the prostate cancer treatments and to rate the pros and cons of each option. The treatment options that are surveyed consist of: 1) surgery; 2) external beam radiation; 3) internal radiation (brachytherapy/seed implants); 4) CyberKnife®; and 5) active surveillance.

In some cases, your rated number should be based upon percentages that are provided in the statement. For example, under the “Con” section of the “Surgery” treatment option, the statement related to cardio-pulmonary complications should take into account the low risk of blood clot formation (2.5%).

Directions:

1. Please rate the four treatment concerns (curability, side effects, pain, and length of treatment) based on a scale of 1-10, with 1 meaning very low concern or importance and 10 meaning the highest concern or importance.
2. Rate each numbered statement again on a rating scale of 1-10, with 1 meaning very low concern or importance and 10 meaning the highest concern or importance. Write your number on the line provided.

3. The treatment option that has the largest difference between the total “Pro” number and the total “Con” number is the option you may be leaning towards. If the difference is small, the validity of that choice may not be as positive as a larger differences. The table below demonstrates the validity of this test.
4. Validity of Decision Choice

0-1 points	Low
6-10 points	Moderate
11 or greater	High

Four Treatment Concerns

(Please rank on a scale from 1-10, with one meaning very low concern or importance and 10 meaning the highest concern or importance.)

1. Curability _____
2. Length of Treatment and Recovery _____
3. Side Effects _____
4. Pain _____

Surgery (Prostatectomy)

1. Surgery will allow the cancer to be accurately staged through pathological exam. _____
2. Urologist will have easy access to lymph nodes to evaluate them. _____
3. Robotic approach will allow for faster recovery (2-3 weeks) and stay (24-48 hours). _____
4. Long-term studies show slightly lower recurrence rates than X-beam at 15 years. _____
5. The PSA test can be used as an accurate predictor of whether the cancer has been completely removed or if it has returned. _____
6. Nerve-sparing technique can reduce impotence rates. _____
7. Surgery can cure prostate cancer, if cancer is localized. _____

PRO's TOTAL _____

1. It is a major operation; the recovery period is 2-3 weeks (robotic) and 4-8 weeks (open). _____
2. Small risk of significant blood loss, so you may need blood transfusions during surgery. _____

3. You may experience erectile dysfunction (impotence). Risk factor: 50-75 %. _____
4. You may experience loss of urinary control (incontinence). Risk factor 8-10% mild; 2-4% severe. _____
5. Small risk of cardio-pulmonary complications, such as blood clot formation. Risk factor: 2.5% _____
6. Can experience pain after surgery, but usually controlled with medication. _____
7. Urinary catheter will be in place post-surgery for 7 days. _____

CON's TOTAL _____

RATIO **PRO's** **CON's**
 _____ / _____ = _____

Radiation Therapy (External Beam)

1. It is performed on an outpatient basis. After your clinic visit, you can go home. _____
2. No surgical risks (hospitalization, bleeding, pain). _____
3. Lower risk of impotence compared to surgery. Risk factor: 30-50%. _____
4. Lower risk of incontinence compared to surgery. Risk factor: less than 5%. _____
5. Low amount of restrictions on working and being active during course of treatment. _____
6. Well tolerated for men in poor overall health. _____
7. External beam radiation can cure prostate cancer, if cancer is localized. _____

PRO's TOTAL _____

1. Long, rigid treatment schedule (6 weeks Monday-Friday). _____
2. Significant fatigue may occur, usually towards the end of treatment. _____
3. May experience frequent bowel movements, diarrhea. _____
4. Risk of impotence (30-50%). _____
5. Small risk of bladder damager: cystitis (inflammation of bladder; painful urination or blood in the urine), usually subsides after several months. _____
6. Common side effect is radiation proctitis: pain, bowel frequency, bowel urgency, and bleeding or rectal leakage. Usually disappears 3-6 months post-treatment. Occasionally, however, symptoms can become chronic in approximately 5% of men. _____
7. Fear that cancer is left in the body. _____

CON's TOTAL _____

RATIO **PRO's** **CON's**
 _____ / _____ = _____

Radiation Therapy (Brachytherapy/Seed Implants)

1. The procedure takes less time than X-beam radiation and is done on an outpatient basis. _____
2. Incontinence rate is 2-5%. _____
3. Studies indicate that it is as effective as X-beam or surgery in the short term (12-15 years). _____

4. The procedure is relatively non-invasive. _____
5. There is minimal effect on sexual dysfunction (20-30%). _____
6. During recovery you will have minimal discomfort that may last a week or so. _____
7. Lower chance of bowel irritation compared to X-beam radiation (20-30%). _____

PRO's TOTAL _____

1. Long-term studies past 12-15 years are not available (recurrence rates). _____
2. It may cause urinary problems: urgency, frequency, burning, irritation, blood in urine, as high as 60%. _____
3. It may cause rectal problems: pain, burning, frequency, urgency (20-30%). _____
4. It may cause impotence. Risk factor: 20-30%. _____
5. May need to provide safe distance between young children and pregnant women for first 2 months. _____
6. After treatment, you are no longer a good candidate for surgery if you have a recurrence. _____
7. Lymph nodes are not evaluated or treated. _____

CON's TOTAL _____

PRO's CON's
RATIO _____ / _____ = _____

CyberKnife®

1. One of the most advanced forms of radiosurgery. A painless, non-invasive treatment that delivers high doses of precisely targeted radiation to destroy cancerous cells. _____
2. Uses a robotic arm that has extreme flexibility to deliver highly focused beams at multiple angles to treat the cancer. _____
3. Continually checks and compensates for any movements you make during treatment, ensuring accuracy. _____
4. Eliminates surgery risks, including potential for infection, complication from anesthesia, and post-operative bleeding. _____
5. Requires no recovery period. Treatments are done on an outpatient basis. Patients undergo their treatments and immediately resume normal activities. _____
6. Patient receives 5 treatments for 1 week, compared to 30 treatments (6 weeks) with external beam radiation therapy. _____
7. Initially has been shown to demonstrate low rates of incontinence (less than 5%). _____

PRO's TOTAL _____

1. There are no long-term studies and/or outcome data for prostate cancer treatment. _____
2. The treatment will take 1 hour, compared to 20 minutes for external beam radiation. _____
3. You will need to have a separate procedure performed (fiducial placement) prior to receiving CyberKnife treatment. _____
4. You will need to use enemas and stool softeners prior to each CyberKnife treatment and will need to carefully watch your diet during treatment. _____
5. You are usually no longer a candidate for surgery if cancer is not eliminated or returns. _____

- 6. Potential for urinary irritability symptoms such as urgency, frequency, or burning on urination (30-40%). _____
 - 7. It may cause bowel irritation such as diarrhea, bowel urgency, and frequency (30-40%). _____
- CON's TOTAL** _____

PRO's _____ **CON's** _____

RATIO _____ / _____ = _____

Active Surveillance

- 1. Some science experts conclude that for some men with early localized cancer (tumor that has not spread outside of the prostate gland) studies show that no available treatment appears to extend life by a significant amount. _____
- 2. There are no immediate adverse effects. Cure-attempting treatment for prostate cancer can lead to incontinence and impotence. _____
- 3. For some men, the choice of watchful waiting means that prostate cancer will produce only minimal impact on their lives and their lifestyles. _____
- 4. Active surveillance is the least expensive treatment alternative in the short-term. _____
- 5. For those who select cure-delaying watchful waiting, it helps to know that treatment choices may be the same later—radical prostatectomy or radiation—as they would have been had they undergone therapy at the onset. _____
- 6. Active surveillance allows you to make a calm and rational treatment decision with your family and your doctor. Prostate cancer can be a very slow growing cancer. _____
- 7. In a few cases, a man chooses active surveillance in hopes that the near future will bring some new discovery that increases the chances of cure. _____

PRO's TOTAL _____

- 1. The main trouble with active surveillance is that it gives the cancer a chance to grow and spread beyond the prostate. _____
- 2. With active surveillance, you're essentially betting that you have some time before the cancer poses a threat. _____
- 3. PSA is not a predictor. Active surveillance involves watching for a rise in your PSA level. As your PSA level rises, so do the odds that the cancer has begun spreading outside the walls of the prostate. PSA levels only give an indirect idea of what is happening with the prostate cancer. _____
- 4. There are fewer options should the cancer spread beyond the prostate during the active surveillance period. Total cure is no longer an option. _____
- 5. If you're the type of man who will feel terribly anxious about harboring a malignant, unpredictable, and potentially lethal disease in your body, active surveillance may lead to a high level of stress for both yourself and your loved ones. _____
- 6. Treatment that begins only after the cancer has spread can be more complicated and unlikely to result in cure. The cost—both financially and emotionally—can be high. _____
- 7. If you live longer than you expected, or if your cancer advances faster than you predicted, you might need to undergo more aggressive treatments or procedures. _____

CON's TOTAL _____

PRO's _____ **CON's** _____

RATIO _____ / _____ = _____