Palo Alto Medical Foundation's Prostate Cancer Care Program

Patient-centered care in a California multispecialty group practice

BY FRANK DELARAMA, RN, MSN, AOCNS; GORDON RAY, MD; AND DANIEL YAO, MD

Our Program At-a-Glance

Palo Alto Medical Foundation (PAMF) for Health Care, Research and Education is a large multispecialty group practice located in California's Silicon Valley. An affiliate of Sutter Health, PAMF employs more than 1,000 primary and specialty physicians in four locations: Palo Alto, Mountain View, Fremont, and Santa Cruz. All PAMF physicians—including primary care and specialty physicians—are members of a partnership. Each year, PAMF sees approximately 250 new analytic prostate cancer cases. These patients receive multispecialty care through PAMF's Integrated Prostate Cancer Care Program at the Palo Alto campus. The Prostate Program offers surgery, radiation therapy, medical oncology, chemotherapy and hormonal treatment, clinical trials, and palliative care and pain management. Radiation treatment modalities include brachytherapy, IMRT, IGRT, and EBRT. Supportive care services include:

- Nurse navigator services
- Patient and family education programs
- Psychological and sexual counseling
- Social services
- Financial counseling
- Nutrition counseling
- Physical therapy services
- Survivorship program and Buddy Program
- Complementary services, such as healing imagery for cancer patients.

At left, PAMF's nurse navigator consults with a patient. Above, radiation oncologist Gordon Ray, MD, with a patient.

PHOTOGRAPHS COURTESY OF PALO ALTO MEDICAL FOUNDATION

Prior to the creation of PAMF's Integrated Prostate Cancer Care Program in 2006, a urology and radiation oncology cancer conference met regularly for well over a decade. Pathologists brought slides to the conference and any PAMF provider could attend. In the early days, mainly retrospective cases were presented to address issues in quality improvement or to discuss rare and unusual clinical cases. This multispecialty format fostered dialogue among providers. Today, these conferences include urology, radiation oncology, and medical oncology, as well as other pertinent specialists. A patient's primary care provider can also choose to attend the conference. Most cases are now discussed prospectively to best determine the individualized treatment plan of care for each patient. The Urology-Oncology tumor board meets formally at least once a month, and ad hoc meetings are arranged as needed.

The driving force behind the creation of an Integrated Prostate Cancer Care Program was PAMF's Patient-Focused Cancer Care (PFCC) Committee. This committee includes nurse managers and administrators from the various

departments that serve cancer patients (Medical Oncology, Radiation Oncology, Urology, Radiology, General Surgery and Plastic Surgery, Health Education, and the Cancer Care Clinic), nurse navigators, and several cancer survivors who were treated at PAMF. The PFCC Committee has met regularly for more than eight years. PFCC Committee recommendations are also routinely reviewed by our physician-based Oncology Committee, and the two committees have become critical in optimizing cancer care at PAMF.

Originally, the PFCC Committee was formed to address issues in patient satisfaction, particularly around streamlining the path from diagnosis to starting treatment for breast and prostate cancer. Today, the committee has expanded to address issues in cancer survivorship, community and provider education, and continues to examine patient satisfaction and improvement for our cancer patients in general.

PAMF's Urology-Oncology Work Group also provided direction to the Integrated Prostate Cancer Care Program. This group is a multidisciplinary team of physicians, including urologists, radiation oncologists, medical oncologists, pathologists, radiologists, administrators, and nurses, including a nurse navigator. The Urology-Oncology Work Group, which has been meeting for more than a decade, runs the monthly urology-oncology conferences.

In addition to these two groups, several environmental factors helped foster the creation of our Integrated Prostate Cancer Care Program, such as a practice provider group of forward-thinking urologists and radiation oncologists, and the practice's non-competitive culture. Shared decision-making regarding prostate cancer treatment decisions is the primary model employed at PAMF (see Figure 1, page 36). The aim is for newly diagnosed patients to come to a final decision themselves, based on numerous objective opinions given by healthcare providers. The nurse navigator guides the patient and family through a comprehensive, prospective assessment of quality-of-life issues that may occur, taking into account their own personal needs and concerns.

Getting Started

Before establishing our Integrated Prostate Cancer Care Program, a team from PAMF that included physicians, nurses, and administrators, visited the Mayo Clinic in Scottsdale, Ariz., and the Forsythe Cancer Center in Durham, N.C., to observe existing multispecialty cancer programs in operation. We used our cancer registry data to identify the number of patients diagnosed with prostate cancer and our outmigration patterns. In addition, the PFCC Committee conducted an environmental assessment looking at all educational and support resources available in the community for prostate cancer. As a result of this assessment, we identified a need for additional resources in the community and worked to develop these resources. Two examples of these new resources include our Buddy Program, which connects newly diagnosed patients with prostate cancer survivors, and the Prostate Cancer Survivorship Care Plan, where with the help of a nurse navigator, a detailed plan is outlined for post-treatment care that addresses physical, emotional, and practical issues for the prostate cancer survivor.

Three additional factors were vital to the success of PAMF's Integrated Prostate Cancer Care Program:

1. Patient feedback
2. A nurse navigator
3. Communication.

The Patients' Perspective

In 2004 and with the help of its diagnosing physicians, PAMF recruited patients and convened several focus groups in an attempt to answer two basic questions: after initial diagnosis—1) why did some patients stay and 2) why did other patients choose to go elsewhere for treatment? Outmigration numbers were small (fewer than 10 patients), but the practice still wanted to identify areas for potential improvement.

These initial focus groups were limited to breast and prostate cancer patients diagnosed within the previous year. We hosted onsite focus groups for patients treated at PAMF; in-depth telephone interviews were conducted with patients who opted for treatment elsewhere to help understand why they had decided to leave PAMF for their cancer care. All focus group participants received a small honorarium for their time.

While the focus groups provided a wealth of information, one fact stood out—patients wanted a coordinated effort from their treating physicians, especially when facing a new cancer diagnosis. We learned that patients were open to the option of having an extended meeting involving all of the cancer specialists soon after diagnosis so that they could thoroughly learn about all available treatment options and the pros and cons of each option. This finding seemed to negate an initial concern that such a multispecialty clinic might be overwhelming for patients and their families.

In the end, the decision to develop our Integrated Prostate Cancer Care Program grew out of these patient focus groups. In other words, it was not a "top-down" decision. Since the development of this program, PAMF has conducted additional focus groups as one method to measure the program's impact on patient perception of quality of care.

Nurse Navigator—the "Glue"

At PAMF, Frank delaRama, RN, MSN, AOCNS, clinical nurse specialist and prostate cancer navigator, is described as the "glue" that brings everything together at the

Integrated Prostate Cancer Care Program. Mr. delaRama came to the practice in 2000 as a radiation oncology nurse. Radiation Oncologist Gordon Ray, MD, identified the need for a nurse navigator for prostate cancer patients, and by 2004, Mr. delaRama's primary role had become prostate cancer nurse navigator, with additional nurses hired to fill his original radiation oncology nursing duties.

He has been a driving force in the multispecialty prostate program since its inception. As the patient navigator of the Integrated Prostate Cancer Care Program, his focus is on shared decision making with the goal of empowering prostate cancer patients to share in the treatment decision-making process. To that effect, PAMF developed and implemented a nurse-delivered, treatment decision-making support intervention. Using a Patient Notebook that includes information and various decision aids, the nurse navigator works with the patient and his physicians to facilitate treatment decision making (see pages 38-39).

The nurse navigator has completed the City of Hope Survivorship Training Program and also serves as PAMF's survivorship coach. Through the Buddy Program mentioned above, the nurse navigator can put newly diagnosed prostate patients in touch with men who've completed a range of prostate cancer treatments.

In 2006, PAMF hired a "cancer care concierge" assistant to the patient navigator. The concierge is a non-clinical staff member who helps with appointment scheduling—providing an important service to our prostate patients.

Prostate Cancer Multispecialty Clinics are held in PAMF's Cancer Care Program, a space set aside for multispecialty clinic visits for breast and prostate patients. Here, newly diagnosed patients meet with several specialists, as well as the nurse navigator and other team members (social worker, dietitian, financial counselor) all in one morning.

EMR Enhances Communication

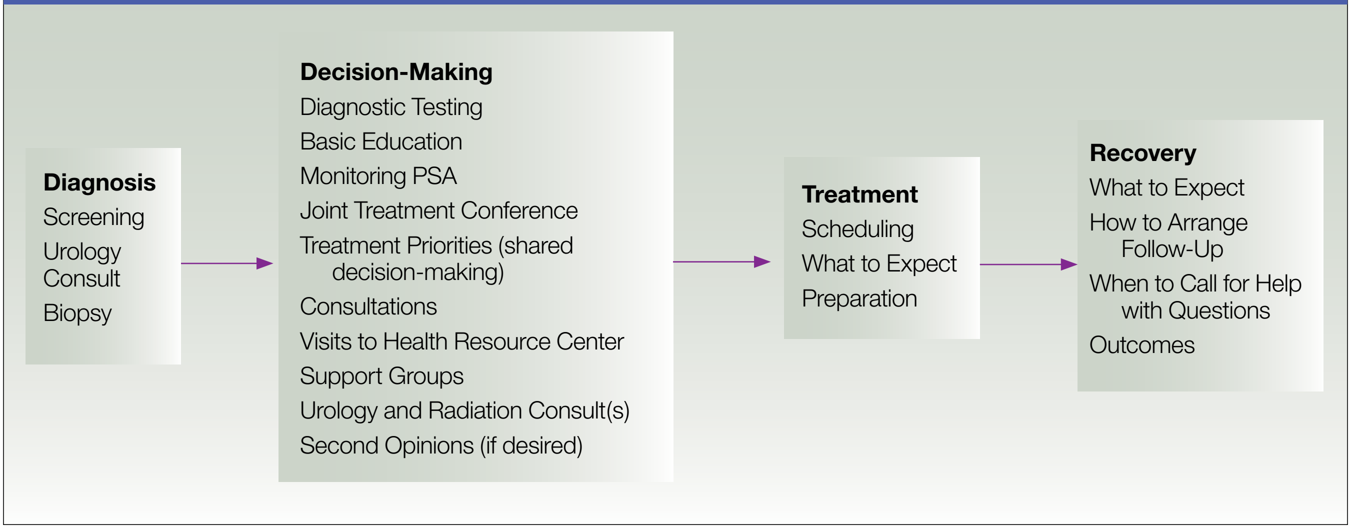
Communication was vital in the development of the robust, patient-centered Integrated Prostate Cancer Care Program. Since 1999, PAMF has employed an integrated electronic medical records (EMR) system that enhances communications among providers and between providers and patients. An integrated EMR allows providers to communicate easily and also allows secure email communication with patients. The EMR has also made ordering tests and medications very easy with minimal chance for any error. When under time constraints, the EMR makes virtual case discussions an option, and allows for review of imaging studies on demand. For the prostate clinic, the EMR is a great communication tool, enabling all involved providers to be aware of specific information provided to patients during physician visits, particularly in terms of treatment decisions. The EMR also helps to keep the patient's primary care provider in the loop through all phases of the prostate cancer care continuum, from diagnosis through treatment and into follow-up care and survivorship. And yet, because providers participating in the Integrated Prostate Cancer Care Program are in one site of service, communication in person or by phone also occurs easily.

Welcome to the Clinic

An important focus of PAMF's Integrated Prostate Cancer Care Program is providing smooth, effortless transitions for patients and families—especially for newly diagnosed cancer patients—among the practice's different departments. Every patient has access to multispecialty patient-team conferences, patient-family-team conferences, individual meetings with radiation oncologists and urologists, and an opportunity to discuss treatment options and the availability of clinical trials. The goal of our program is for patients to make well-informed treatment and disease management decisions. The patient treatment team may include the following:

- Medical oncologist
- Radiation oncologist
- Urologist
- Oncology nurse
- Nurse navigator
- Social worker and/or counselor
- Financial counselor
- Pharmacist
- Physical therapist
- Dietitian.

Figure 1. Prostate Cancer Decision-making and Care Flowchart



Here is how a typical patient might move through our program. The primary care physician oversees the patient's prostate cancer screening (PSA checks, yearly DRE), and if there is anything of concern at these visits, the patient is referred to Urology for consideration for prostate biopsy.

If the prostate biopsy comes back positive, the urologist is the first to know. At this point in the process, urologists will routinely refer patients to the nurse navigator. The urologist will either call or email the prostate nurse navigator who will arrange either a multispecialty clinic meeting or a traditional meeting consisting of a set of several separate appointments. The type of meeting scheduled is based on patient preference (some patients may be too overwhelmed with a multispecialty meeting) or physician scheduling.

PAMF follows NCCN Prostate Guidelines for the multispecialty prostate clinic to provide a firm foundation for all the medical specialty opinions given to newly diagnosed prostate cancer patients. The clinic is usually held on Friday mornings. If needed, patients can be accommodated on other days as well, schedules permitting. In one morning the patient can meet with a surgeon (urologist), a radiation oncologist, and the nurse navigator. Patients are introduced to supportive care resources and provided with information on these services, which are available free to patients. Patients can also meet with a social worker and nutritionist; however, meetings with supportive care staff are usually scheduled for another date because the multispecialty clinic can run as long as three hours.

The prostate nurse navigator tries to connect with every newly diagnosed prostate cancer patient as soon as possible either by phone or email. Each patient is offered an office visit/education session, an opportunity to discuss his case individually. Patient navigation services are provided to patients free of charge.

If a patient is unable to attend a multispecialty clinic, the navigator ensures that the patient gets the information he needs. If the patient arrives with a packet of information and asks for help, the nurse navigator explains the educational materials in more depth. If the patient wants a second opinion—either internal or external—the nurse navigator helps facilitate the appointment. The nurse navigator also arranges follow-up appointments for imaging, radiation therapy, and more. PAMF recognizes that the nurse navigator, who helps patients from diagnosis through decision making and treatment, has often developed a great relationship with the patients and their families, so once treatment is done, the navigator becomes the patient's cancer survivorship coach and compiles a detailed survivorship plan for the patient. For those patients who do not want a formal survivorship plan, the patient navigator remains a resource.

Marketing the Program

Once the Integrated Prostate Cancer Care Program was up and running, the next obvious step was to educate referring physicians, patients, and the community about the program. To date, our marketing efforts have focused on:

- Revamping the website of the Integrated Prostate Cancer Care Program (*www.pamf.org/prostate*)
- Arranging for the prostate nurse navigator and physicians to speak at community events on such topics as "Prostate Cancer: An African-American Crisis Revisited," "Prostate Cancer: Concerns for Latin-American Men," and "The Genetics of Prostate Cancer."
- Hosting several prostate survivors' panel discussions that included physician participation.
- Offering a DVD describing the patient experience at PAMF. This DVD was created as a personal project by a former patient with a background in broadcasting.

Outcome Measures

An integrated prostate cancer care program can serve as a springboard for quality improvement projects.

PAMF uses a Press Ganey survey to measure patient satisfaction—quarterly for all patients in the practice—and an outbound phone survey to measure patient satisfaction on physician-related issues. Currently, these measures are not specific to the Integrated Prostate Cancer Care Program; however, in 2010 PAMF will implement an oncology-specific Press Ganey survey for patient satisfaction.

The Integrated Prostate Cancer Care Program has used repeat focus groups as one way to measure improvement in patient satisfaction. The program surveys patients on quality of life issues at 3 months and 1 year post-treatment.

PAMF is also developing a disease-site-specific program to measure satisfaction in its prostate cancer patients. This program will incorporate validated measures (e.g., EPIC-26, City of Hope Cancer Survivor QOL Questionnaire) to develop a tool that will be administered by phone or through the Internet.

This research project is designed as a two-year intervention pilot test with a historical control. The study will look at patient quality of life outcomes for those who received PAMF's nurse-delivered treatment decision-making support intervention (prostate nurse navigator services utilizing PAMF's Patient Notebook with information and various decision-making aids) versus outcomes for men diagnosed during a period when the intervention was not available. Outcome measures include decisional conflict, the interval between diagnosis and treatment decision, treatment chosen, prostate-cancer-specific quality of life, prostate-cancer-specific anxiety, general health-related quality of life, and health resource utilization.

Future Directions

Given the success of the Integrated Prostate Cancer Care Program, PAMF plans to expand the clinic model to other practice locations; however, radiation oncology services will continue to be provided at only one site of service. If the program expands, the administrative burden of running the multispecialty care program (i.e., consent forms, educational materials developed for the current multidisciplinary clinic, etc.) will be shared among all practice sites. In this way, PAMF will achieve economies of scale while providing individualized patient care.

Additional future plans include increasing awareness of PAMF's prostate survivorship program and post-treatment directed-care plan. PAMF's survivorship plan includes such post-treatment planning as psychosocial support, shared decision-making, nutrition support, a pain management plan, and charitable care.

Frank delaRama, RN, MSN, AOCNS, is clinical nurse specialist and prostate cancer navigator; Gordon R. Ray, MD, is chairman of the Department of Radiation Oncology; and Daniel Yao, MD, is a urologist at the Palo Alto Medical Foundation, Palo Alto, Calif.

Palo Alto Medical
Foundation
A Sutter Health Affiliate

Shared Decision-Making Process

With contributions from Nancy L. Brown, PhD, Palo Alto Medical Foundation Research Institute;
Gordon Ray, MD, Palo Alto Medical Foundation;
and D. Jeffrey Demanes, MD, California Endocurietherapy Cancer Center.

Step 1: Where do I start?

My risk group is: ____

Doctor-recommended treatment options

Rank your options ("1" being the best option, or describe)

Low Risk of Recurrence
____ Watchful waiting
____ Surgery
____ Radiation (external beam and/or brachytherapy)

Intermediate Risk of Recurrence
____ Watchful waiting
____ Radiation (external beam and/or brachytherapy)
____ Surgery

High Risk of Recurrence
____ Hormonal therapy plus radiation
____ Surgery and radiation

Describe, if different:

____

Step 2: Identifying my Goals (Rank your goals, "1" being the most important.)

My Prostate Cancer Goals are:

______ **Avoiding Side Effects**

Vignette 1: Age 73 (T2a, Gleason = 6) "The thought of being incontinent or needing a diaper depressed me…the options were surgery or radiation, and I thought proton therapy might reduce the possible side effects…and I have been extremely satisfied."

______ **Maintaining Quality of Life**

Vignette 1: Age 55 (T1c, Gleason = 7) "I am a young, sexually active gay man…I am unwilling to consider living the rest of my life without erections…I chose to watch and wait."

Vignette 2: Age 83 (T3b, Gleason = 9) "I wanted to stay active. I golf, ski, and work part time. I did hormones, then brachytherapy, then external beam radiation."

______ **Getting the Cancer Out/Gone**

Vignette 1: Age 78 (T1c, Gleason = 8) "I wanted to get rid of the cancer and live longer. Radiation was the best option. I did hormones while I was deciding what treatment to pursue."

Vignette 2: Age 58 (T2a, Gleason = 7) "I wanted to get rid of the cancer and know more about the disease. Surgery was the best option."

_______ **Making Treatment as Convenient as Possible**

Vignette 1: Age 63 (T1c, Gleason = 6) "I wanted a short treatment phase, fewer complications, and a short recovery time. HDR brachytherapy was best for me."

Vignette 2: Age 63 (T1c, Gleason = 5) "I am the primary caretaker for…and I have a job that requires my presence. I had to be able to miss zero days of work. I chose permanent seed brachytherapy."

Step 3: Setting Priorities (Rank your priorities, "1" being the most important)

My priorities for treatment are:

____ **Avoiding *immediate* side effects of treatment**

____ Incontinence

____ Urine ____ Bowel

____ Impotency/erectile dysfunction

____ Bowel problems

____ Other (Please specify:______________________
______________________________________)

____ **Avoiding *long-term* side effects of treatment**

____ Incontinence

____ Urine ____ Bowel

____ Impotency/erectile dysfunction

____ Bowel problems

____ Other (Please Specify:____________________
______________________________________)

____ Sexual potency (long- and short-term)

____ Control cancer/life expectancy

____ Quality of life

____ Convenience

____ Number of treatments

____ Where treatment is administered

____ Cost

____ Operative risk (fear of dying during surgery)

____ Other (Please Specify: ____________________
______________________________________)

Step 4: Making a Decision

My realistic options are:

Priorities	**Option 1**	**Option 2**	**Option 3**	**Option 4**

The next steps I need to take are:

Find more information	**Date I expect to accomplish this goal:**	**Support I need:**
1.		
2.		
Talk to family members		
1.		
2.		
Make appointments		
1.		
2.		

Patient signature: ______________________________ Date: ______________

Navigator signature: ______________________________ Date: ______________