



Information, Coordination, Navigation: The Keys to Improving the Patient Experience

Jay C. Andersen, M.D.

Medical Director, Breast Cancer Consultation Service, Northwest Cancer Specialists

Dawn Barringer, R.N., B.S.N.

Breast Health Navigator, Cancer Centers of North Carolina

Susan Russell

Founder and CEO, The Russell Mark Group

You can see her now—the patient who comes to the practice for the first time to talk about her cancer. There is so much she needs to know, much more than 30 or even 60 minutes will allow. Though physicians try hard to present all her options clearly, with compassion and assurance, the overwhelming nature of the diagnosis means that this conversation is not enough. Then there are the endless appointments, the coordination among all the providers, the test results to juggle and explain. With each step in her treatment regimen, new questions arise for the patient—many she never even asks.

Cancer treatment is a complex disease state to manage. It involves multiple specialists with different points of view, often located in different places. Layer upon layer of decisions must be made together with the patient and the family, with every option examined and explained. What type of surgery, chemotherapy and/or radiation? What about reconstructive surgery? Side effects? The impact of the treatment regimen upon the patient's life leads to another level of complexity. What about the patient's job and family? How will he or she get to all of these appointments? Who will pay? As advances are made in treatment, the options and decisions they require simply increase.

Information Gap

A widely cited 1990 patient satisfaction study published in *Cancer*¹ found that while cancer patients were satisfied overall with the quality of the care they received, few were satisfied with the information they were given concerning their disease and their treatment options. Another study² showed that, when choosing from 12 specific information and support topics, patients chose information as their greatest need. Since these studies were published, the Internet has rapidly become an important resource for medical information in general and cancer information in particular—cancer is the number one disease researched on the Internet. But a paper by Mills and Davidson³ showed that when cancer patients were asked where they obtained most of their information about the disease, the vast majority still relied primarily on their own care team. Clearly the wonders of the Internet have not diminished the need for patients to understand their own unique situations and get information from those they know and trust.

Perspectives

Even though most patients rely on their providers for information about their disease, it isn't always easy for them to get it. Yet having good information gives patients a sense of control, relieves anxiety, and equips them for the road ahead. Interestingly, Butow et al. found that a cancer patient's psychological health depended more on the quality of the discussion about treatment options than the severity of the diagnosis⁴. In addition, according to a study on patient satisfaction among breast cancer patients, when patients receive diagnosis and treatment options in an unhurried, supportive setting, they are better equipped to make appropriate therapeutic choices⁵.

The Chaos of Care

A British study recently reported that within the first year after diagnosis, cancer patients had met an average of 28 doctors⁶. Juggling dozens of appointments, traveling to different sites for different procedures or treatments, and chasing test results are all part of the stress of cancer for most patients. An article in a recent issue of the *Journal of the National Cancer Institute*⁷ estimated that the value of patient time lost to cancer care was nearly \$2.3 billion in the first year following diagnosis alone, in the millions of hours traveling to and from, waiting for, and receiving treatment.

Added to this is the anxiety of daily tasks left undone because of the illness—children who need care, a job that is set aside, other family members who rely on the patient, or a home untended. Although financial pressures could be mounting, the patient and family may not have the time or energy to investigate assistance programs. The result too often is an overwhelmed, isolated patient and an exhausted family.

Enter the Patient Navigator

A new professional, the patient navigator, has arisen within the care environment to address these two crucial issues—the need for regular, specific information in a supportive environment and the need for help coordinating care. The National Cancer Institute defines the role as one who offers “assistance to healthcare consumers (patients, survivors, families, and caregivers) to help them access and then chart a course through the healthcare system and overcome any barriers to quality care.” The first well-known program was developed by Dr. Harold Freeman at the Harlem Hospital in the early 1990s, with large academic hospitals and health systems quickly following. Kaiser Permanente Southern California included a “patient coordinator” as part of its influential Breast Buddy Care Program launched in 1994, defining the role as “an advocate [who] addresses common communication problems and the complexity involved in breast cancer treatment decision making.” The concept has now found its way into community cancer care.

A good example of the navigator at work in a community practice is Northwest Cancer Specialists in Portland, Ore. Physicians of the practice recognized the need to provide “more encompassing” care to their patients and developed their Breast Cancer Consultation Service around the patient navigator concept in 2005. As a differentiating element at Northwest Cancer Specialists, the navigator contacts patients even before they arrive for their first appointment to initiate discussion, offer support and education, and help allay fears.

Although the requirements of the position vary widely, patient navigators typically meet with patients following diagnosis, providing them with information about the disease state in general—most patient navigator programs are disease specific—and their situation in particular. They will review and explain pathology reports and staging tests, walk through the steps of treatment, coordinate appointments, and delve into the support programs available to the patient along the way. Once treatment has begun, the navigator continues to talk regularly with the patient about reactions and side effects, answering questions and learning about other ways the patient may need logistical help or emotional support.

An important function of the navigator is to be a familiar, consistent presence throughout the patient's course of treatment. Rather than placing a call to a phone bank of nurses, a patient can call someone he or she already knows and get a personal answer to a question. Because cancer treatment involves such a large cast of players, patients benefit greatly from having a single person to rely on for informational, tactical, and emotional support.

Physician Perspective

The benefits are especially evident to physicians. Since many studies have shown that patients retain only a small percentage of what the doctor says during appointments, particularly when a cancer diagnosis is under discussion, extra effort is clearly needed to help the patient understand the steps and implications of his or her care.

Cancer Centers of North Carolina saw the need patients have for a supportive and consistent partner through the diagnosis and treatment of breast cancer and implemented a patient navigator program to guide patients through the experience. In this program, like the one at Northwest Cancer Specialists, every patient is presented with a ring binder with personalized information that highlights her diagnosis, individualized treatment plan, and detailed educational and support information, including pathology reports and lab data, information on chemotherapy and radiation, and web sites for support groups.

Although some navigator roles are filled by non-clinicians, a clinical background can make a big difference. Palsson and Norberg found that when nurses provide information and emotional support, patients reported a greater sense of control and greater satisfaction with their care⁸. The approach also frees up time for the provider, who is greeted with a better prepared, better informed patient during scheduled appointments and who receives fewer questions between appointments. “We think patients get better care this way,” Elizabeth Campbell, M.D., a medical oncologist at the Cancer Centers of North Carolina, said. “Their side effects are constantly monitored by someone who knows what to look for, they’re checked on, and they receive very directed information.”

The response for both Northwest Cancer Specialists and Cancer Centers of North Carolina has been overwhelmingly positive. Patient satisfaction has increased and referrals from surgeons have also gone up. “It’s not an inconsequential cost, but it’s a gratifying benefit,” Dr. Campbell said. “Anything that makes the patient happier and more comfortable with her care, makes her care better.”

Although advances in cancer care bring hope to many, they often do not improve the experience of the patient undergoing treatment. By providing continuous, targeted information in a supportive setting and offering consistent help with the myriad tasks of treatment coordination, practices can do much to help patients navigate their way through this complex journey.

Impact on the Community Practice

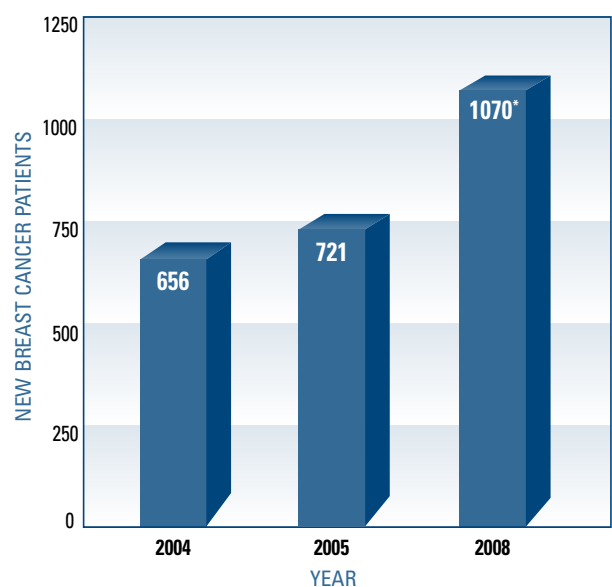
Compassionate care and better patient outcomes improve the overall patient experience and benefit the community practice.

Northwest Cancer Specialists in Portland, Ore., is a pioneer in the patient navigator concept as a vehicle to improve patient satisfaction. The practice launched its Breast Cancer Consultation Service in 2005, comprised of eight medical oncologists, two radiation oncologists and a patient navigator, to increase patient access to information and provide a collaborative, coordinated, and timely approach to care. A communications campaign followed, aimed at local referring physicians and the public, to share information about the program and its benefits.

Overall patient volume has increased 63 percent since the program began, or an average of nearly 16 percent per year, in spite of the departure of a physician in 2006 who was not replaced until late 2007.

Northwest Cancer Specialists plans to continue to evaluate the program through metrics such as new patient volume, chart review, use of clinical pathways, and financial performance.

NORTHWEST CANCER SPECIALISTS



* Estimate

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Jay C. Andersen, M.D.

Medical Director, Breast Cancer Consultation Service, Northwest Cancer Specialists

Jay C. Andersen, M.D. is board certified in oncology, hematology, and internal medicine. He was a member of the initial physician team that conceptualized and implemented the Breast Cancer Consultation Service at Northwest Cancer Specialists in Portland, Ore., and is currently the director of the program. Certified as a US Oncology Center of Excellence, this program serves as the template for implementation of the patient navigator program across the US Oncology network.

Dr. Andersen received his medical degree from The University of Kansas. He completed his residency in internal medicine and fellowship in hematology/oncology, with special study in breast cancer, at the University of Kansas Medical Center.

Dawn Barringer, R.N., B.S.N.

Breast Health Navigator, Cancer Centers of North Carolina

Dawn Barringer serves as the Breast Health Navigator at Cancer Centers of North Carolina in Raleigh, a role she originated at the practice a year ago. She has 18 years experience in the area of oncology, including inpatient and outpatient oncology services, chemotherapy infusion, radiation education and triage, HDR nursing support, and home infusion.

Dawn is a graduate of Indiana University with a Bachelors in Nursing. She has worked across the country, from Los Angeles, Calif., to Indianapolis, Ind., and Raleigh, N.C. With the US Oncology certified Center of Excellence at Cancer Centers of North Carolina in Raleigh, she guides patients through their treatment with personal, coordinated care and support.

Susan Russell

Founder and CEO, The Russell Mark Group

As the founder and CEO of the Russell Mark Group, a leading verbal branding consultancy, Susan Russell is a specialist in branding, naming, writing, and other language of the marketplace. She has been quoted on branding and language issues in the *San Jose Mercury News*, *Boston Globe*, *Wired*, *California Medicine*, and the *Milwaukee Journal Sentinel*.

In addition to US Oncology, her clients include Carnegie Mellon University, Visa, Procter and Gamble, Hill-Rom, SAS Institute, Kaiser Permanente, and Blue Shield of California.

Before founding the Russell Mark Group, she was an information designer with the international consultancy Fitch, Inc. She has also been director of publications at Princeton University and the Rockefeller Foundation, where she devised and implemented a new communications program.

Susan holds a Master of Arts in English with an emphasis in linguistics from Miami University, Oxford, Ohio.

For more information:

Call: (800) 381-2637

E-mail: oncology.info@usoncology.com

www.usoncology.com

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