

Now What?

A community hospital keeps connected to cancer survivors

By Nancy Heifferon



With the ranks of cancer survivors swelling fast, who is following survivors post-treatment to ensure that they are screened regularly for new or recurring cancers? Who is collecting lifelong data about the late effects of their treatments? Who is providing comprehensive, individualized survivor care plans that address the needs of the whole person?

For a start, Thomas Johns Cancer Hospital (TJCH), a community hospital in Richmond, Virginia. TJCH is a recognized leader in the emerging area of survivorship. The hospital is working on solutions for long-term patient follow-up that are effective for community treatment centers as well as academic hospitals. Key elements of the TJCH program are dynamic customized care plans and a lifetime connection to survivors, made possible by web-based EQUICARE CS™ survivorship management software from Cogent Health Solutions tied into the ARIA® oncology information system from Varian.

“Apples and watermelons”

Community hospitals like TJCH face severe challenges when it comes to caring for cancer survivors. “They diagnose and treat 80 percent of all cancer cases in the United States,” explains Mark Thomson, vice president of sales and marketing for Cogent Health Solutions. “Yet they lack the resources and funding of large academic medical centers for the third phase of cancer care: survivorship.”

Furthermore, community hospitals are already feeling the brunt of a shortage in oncologists, which is projected to worsen. While the demand for oncology services is expected to grow by 48 percent between 2007 and 2020, the supply is expected to grow only by 14 percent. This imbalance of supply and demand translates into a shortfall in the United States of as many as 4,080 oncologists by 2020.¹ While most oncologists believe it is their responsibility to provide continuing survivor care, there just aren't enough of them to address the needs of a survivor population that is growing at an accelerating rate.² Their first priority has to be the timely diagnosis and treatment of new cases.

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“It’s apples to watermelons,” says Steven Castle, TJCH administrator, explaining the magnitude of the challenge for community hospitals. “For example, at our hospital we treat 1,800 active cancer cases per year, but are we tracking about 20,000 cancer survivors right now.”

It is no wonder then that cancer survivors, who receive the highest quality care during the active phase of their treatment, can sometimes feel abandoned or lost after their last radiation or chemotherapy treatment or their last appointment with the surgeon. More than a decade after the National Coalition for Cancer Survivorship published its 12 principles for quality cancer care, which included the right to long-term follow up care, many survivors are still waiting their needs to be addressed. In fact, 49 percent of survivors who responded to an online poll conducted by the Lance Armstrong Foundation say they have unmet survivorship needs.

Tina P., a three-year survivor of inflammatory breast cancer, knows how they feel. Treated at another community hospital, she found the cancer resource center at TJCH the same way she manages her own survivorship today—by being proactively involved in her own care and seeking out information and resources. “After treatment, I had scarring that has made it difficult to live pain free,” Tina explains. “I had surgery, chemotherapy, and radiation therapy, but none of those specialties really tackle the leftover issues. Somehow treatment-related medical issues need to be better addressed.”

At TJCH, they couldn’t agree more. “We are doing such a good job in the treatment of cancer,” says Castle about the medical profession at large, “that we created this huge population of survivors. So the next logical step, in our opinion, was to address their continued well being.” TJCH took that next step by seeking partners. Varian and Cogent Health Solutions helped the hospital develop a survivorship management program that would meet patients’ needs while easing the burden on overstretched oncologists. “We didn’t want to wait for somebody else to do it. We didn’t want to wait for the guidelines to be well established. We knew we weren’t,

as a community-based hospital, going to get a research grant to fund our survivorship initiative,” explains Castle.

Three pillars of a survivorship system

TJCH and its partners built the survivorship program on three pillars. The first pillar is physician control. “Our program is different from some established survivorship clinics,” says Castle. “In our program, physicians understand that they remain in control.” Adds Tricia Cox, director of the TJCH survivorship program, “Physicians can refer patients to the nurse practitioner or continue to follow patients themselves, and we will support them. It’s their choice.”

Flexibility is the second pillar of the survivorship system. “The survivorship case management system we have can be implemented anywhere from a free-standing cancer clinic in a small community to a large urban academic medical center,” says Castle. “It provides the tools needed to deliver customized survivorship care on any scale.”

The third pillar is engagement. A successful survivorship system must connect and engage the oncologist and the patient—and the primary care physician. When patients enter into cancer treatment, primary care physicians are often left out of the loop, with potentially serious consequences.

The primary care physician may not see patients who are referred to cancer specialists for many months, during which time other medical issues such as blood pressure and diabetes may worsen. “Patients with major illnesses such as cancer usually focus only on that major problem and sometimes ‘forget’ about other comorbidities,” says James Joseph, MD, a primary care physician who helped TJCH define its survivorship program. “When the primary care doctor remains involved, problems can be resolved and the patient stabilized more quickly.” Sometimes, says Joseph, “Primary care physicians are not even aware that the patient has expired until we see a relative or receive a death certificate for signature. This is quite devastating for the family and the primary care physician.”



1. See *Forecasting the Supply of and Demand for Oncologist*, a report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies, 2007.
2. See “Survivorship,” from *Elevating the Patient Experience*, p. 63, published by The Advisory Board, 2008.

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Joseph’s recommendations for any cancer survivorship program include a comprehensive treatment plan with the role of the primary care provider clearly outlined, regular progress notes from the treating cancer specialist, and referrals back to the primary care physician for management of medical issues such as hypertension or diabetes. “Cancer survivors should be encouraged to follow up with their primary care physician,” emphasizes Joseph.

A dynamic care plan

The TJCH survivorship program has taken action on these recommendations, as well as those of cancer specialists and patients.

At the conclusion of treatment, the patient receives a customized care plan that is a survivor roadmap. It includes a

Steven Castle, Thomas Johns Cancer Hospital

summary of all treatment delivered and a lifetime schedule for follow-up screenings and appointments. It provides information about the short- and long-term treatment side effects that could occur. It includes individualized guidance about diet and exercise. The plan even includes referrals to support services appropriate to the individual. EQUICARE CS case management software generates the plan automatically, pulling information from the electronic oncology medical record (the ARIA oncology information system from Varian). A plan that would take hours of manual effort to assemble is generated with the click of mouse.

The electronic care plan can do much more than a static paper document. It generates reminders about follow-up events, such as screenings or lab tests, or alerts that scheduled events have



A State-of-the-Art Community Hospital

Founded in 1982, the Thomas Johns Cancer Hospital (TJCH) is located on the Johnston-Willis campus of the CJW Medical Center in Richmond, Virginia. CJW has long maintained the highest level of accreditation that a community hospital can attain from the American College of Surgeons Commission on Cancer, and

recently received that organization’s Outstanding Achievement Award. A model for comprehensive and integrated care, it serves inpatients and outpatients with surgery, medical oncology, radiation oncology, gynecology, urology, and support services, all under one roof. *Image courtesy of TJCH.*

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James Joseph, MD, primary care physician

been missed. These notifications can go to the nurse practitioner, the physician, or the survivor.

Survivors also receive secure access to their individual care plans over the Internet. Having the plan online enables two-way interaction between survivors and healthcare providers. The healthcare provider can collect feedback from the survivors about satisfaction. Certain cohorts of survivors can be surveyed online to collect data for analysis. Primary care physicians also have a secure portal where they can view their patients' care plans and obtain information about post-treatment issues they may be experiencing.

“EQUICARE CS tears down the silo walls that exist between the medical oncologists, the radiation oncologists, and the surgical oncologists by enabling them to exchange information more freely. It also builds a bridge to the primary care physician. It's a beautiful system,” says Castle. And, he adds, “It's pretty easy to implement if you have Varian ARIA products.”

Moving ahead

Thomas Johns Cancer Hospital started its survivorship program with 12 breast cancer patients and is expanding from there. As multiple organizations, such as the American Cancer Society, the National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO), and the American Society for Therapeutic Radiology and Oncology (ASTRO) publish their separate guidelines for survivor care, TJCH is implementing them in its survivorship program. NCCN added a survivorship section to its colorectal treatment guidelines in February 2009, so next up are care plans for colorectal cancer survivors. “Our medical staff reviews and validates the care plan template, and we implement their choices. We aren't waiting for all these organizations to reach agreement on the guidelines,” says Castle.

TJCH sees the survivorship program as a means to grow loyal patient relationships. Meeting the demands of survivors for individualized follow-up care is likely to increase their satisfaction and bring them back to TJCH for their regular scans and tests. Furthermore, better follow-up care and earlier intervention when health problems do arise can lower the overall long-term cost of healthcare for survivors.

The response to the TJCH survivorship program has been overwhelmingly positive from all quarters. “We engaged cancer patients, cancer survivors, oncologists, primary care physicians, and IT in the development of the program,” concludes Castle. “Everyone we talk to loves the program.”

Nancy Heifferon is a freelance healthcare writer.

THE DECLARATION OF CANCER SURVIVOR RIGHTS

Survivorship programs stem from two of the guiding principles articulated by the National Coalition for Cancer Survivorship.

Principle 6: People with histories of cancer have the right to continued medical follow-up with basic standards of care that include the specific needs of long-term survivors.

Principle 7: Long-term survivors should have access to specialized follow-up clinics that focus on health promotion, disease prevention, rehabilitation, and identification of physiologic and psychosocial problems. Communication with the primary care physician must be maintained.

To learn more, visit the National Coalition for Cancer Survivorship's “Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability” at <http://www.canceradvocacy.org>.

