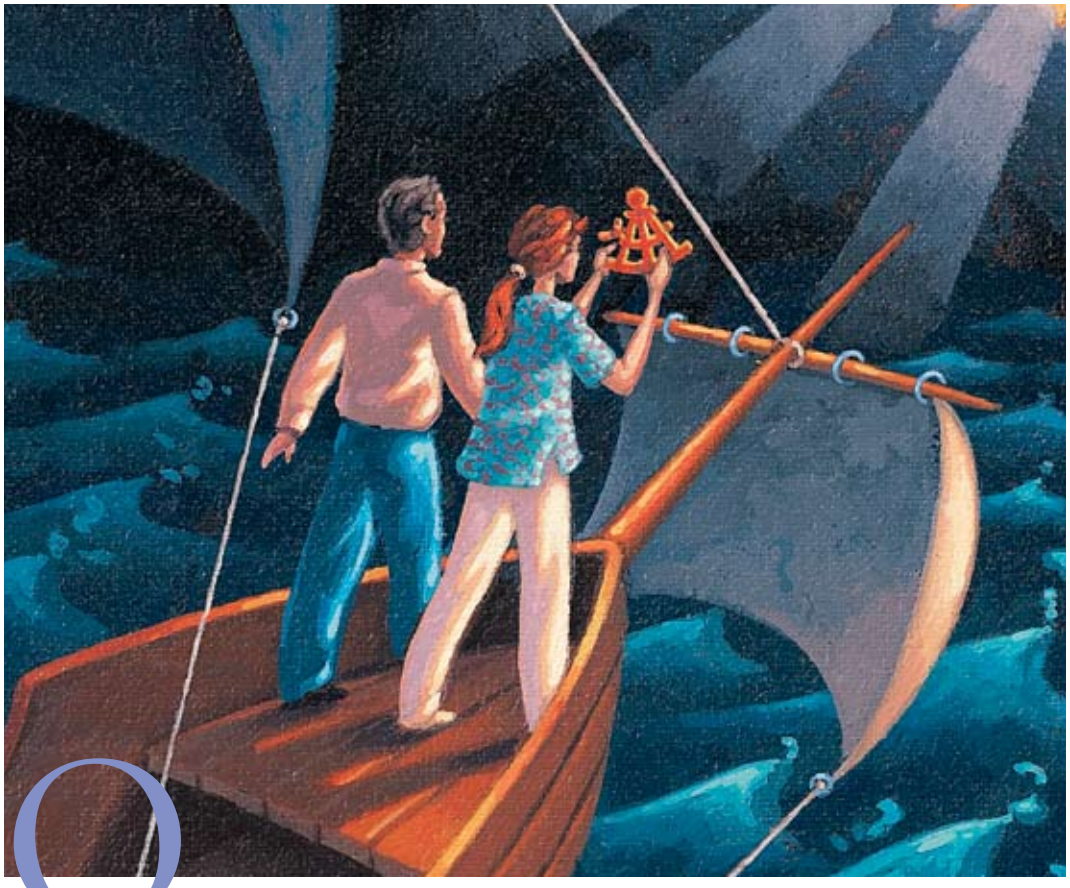
Oncology Nurse Care Coordinators as "Navigators"

Improving cancer disease management and the patient experience



Oncology nurses have always played a crucial role in coordinating physicians, other cancer center staff, and cancer patients. An equally important function has been to connect cancer patients to resources and information related to their cancer diagnosis, treatment, and follow-up. It usually falls to the oncology nurse to translate this complex information for patients and to "navigate" patients through an equally complicated healthcare delivery system and "connect" them to cancer center staff.

Since 2000, Christiana Care Health Services (CCHS) in Newark, Del., has assigned a certified oncology nurse with at least five years of clinical experience to all new CCHS cancer patients—regardless of whether the patient was seen in the hospital or in a physician office affiliated with the hospital.

In June 2002, CCHS opened the 60,000-square-foot Helen F. Graham Cancer Center to offer streamlined, multidisciplinary care to Delaware residents. In its first year, the cancer center had more than 60,000 patient visits. Since then, about 2,700 new analytic cancer patients are treated each year.

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ILLUSTRATION/ERIC WESTBROOK

After looking at the state's cancer registry data, CCHS discovered that a majority of Delaware's advanced cancer patients lived in one or two Wilmington zip codes. To better reach this underserved patient population, CCHS expanded the outreach efforts of its oncology nurse care coordinator program, promoting prevention and improving access to care in that specific geographical region. Staff at the cancer center developed 10 disease management objectives to help its oncology nurse care coordinators educate at-risk patients about a variety of issues, including understanding diagnosis recommendations and treatment options, compliance, clinical research options, and second opinions (see Table 1, page 28).

Oncology Nurse Care Coordinators

These oncology nurses have numerous responsibilities, including assessing the medical, emotional, and social needs of all cancer patients; coordinating access to social workers and other oncology staff; and developing patient education materials. They also help cancer patients resolve a wide variety of transportation, medication, health insurance, and financial issues. (See box below for a more complete list of these responsibilities.)

Patient through-put is high. Between 60 and 80 inpatient cancer patients are assessed daily by oncology nurse coordinators and/or social workers; each month, oncology nurse care coordinators each carry a caseload of 125 cancer patients. Utilization of other cancer center staff is as follows:

- Social workers see a monthly average of 250 cancer patients each.
- Dietitians see a monthly average of 200 visits.
- A genetic counselor has about 107 patient visits each month
- A health psychologist treats about 100 patient visits per month.

Working in Tandem with the Team

At the Helen F. Graham Cancer Center, oncology nurse care coordinators arrange patient appointments, including those made with laboratories and specialty physicians, taking care to streamline patient visits whenever possible. For example, radiation therapies are now arranged to avoid treatment breaks for patients. Each cancer patient is scheduled to meet with a multidisciplinary disease site center (MDC). At this meeting, the patient consults with a team that typically consists of a surgeon, a radiotherapist, and a medical oncologist. Other specialists are called in to consult as needed. For example, the head and neck cancer MDC may include a dental specialist, a plastic and/or vascular surgeon, and a speech therapist. Frequently, pathologists and radiologists may be

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Responsibilities of Oncology Nurse Care Coordinators at the Helen F. Graham Cancer Center*

Patient Responsibilities

- Assess the medical, emotional, and social needs of cancer patients
- Help patients and their families understand their problems and the resources available to them
- Act as a "link" between patients and all other care providers
- Coordinate access to other cancer support staff, including social workers, dietitians, and physicians
- Help arrange appointments for consultations and support services
- Encourage patients to keep and update their own medical records
- Educate eligible patients about appropriate research studies
- Educate patients about appropriate new technologies, such as Mammosite, Gliasite, and Sir Spheres.
- Coordinate in discharge planning with the patient's family, social workers, home nursing staff, oncologists, and personal physicians
- Work with patients and family members to ensure discharge instructions are understood and followed.

Professional and Staff Responsibilities

- Encourage and participate in multidisciplinary concurrent consultations and/or tumor conferences
- Document recommendations made at multidisciplinary consultations and/or tumor conferences
- Assist health improvement teams (HITs) to keep cancer site programs up-to-date and stimulate performance improvement studies (see page 30).
- Help with cancer disease planning and compliance with safety issues
- Help develop patient education programs and tools
- Help develop understandable standing order forms
- Coordinate with in-hospital care management resources
- Seek professional growth and attend in-service educational programs
- Work with tumor registry staff
- Aid in tissue procurement for research purposes (when necessary).

*The oncology nurse care coordinator role is not limited to the above list.

Since 2000 and with the help of other nurses, social workers, and key support personnel, oncology nurse care coordinators (pictured at left) have navigated more than 15,000 patients through the Christiana Health Care System.

Job satisfaction is high for these oncology nurse care coordinators. LaTonya Mann-Jamison, RN, is one of nine nurses who work together as a cohesive team, helping cancer patients and family members at the Helen F. Graham Cancer Center.

Oncology nurse care coordinators work closely with physicians, research nurses and data managers, and other support staff to provide quality care to cancer patients.

Multidisciplinary Disease Site Centers

1. Breast
2. General oncology
3. Genitourinary
4. Gynecology
5. Head and neck
6. Hepatobiliary/ Pancreas
7. Lymphoma
8. Neuro-oncology
9. A pain consultation team
10. Rectal/Anal
11. Thoracic/esophageal
12. Young adult
13. Melanoma
14. Sarcoma

part of an MDC. (See box above for a list of all 14 MDCs.)

Twelve tumor conferences are scheduled each month. Most are problem cases, with a few cases selected due to academic interest. In addition, the cancer center hosts several yearly conferences and ad hoc hospital meetings, which cover issues related to medical, pediatric, and surgical oncology. Sectional conferences also take place; for example, in radiotherapy. Oncology nurse coordinators attend all these conferences, especially if their cancer patients are being discussed.

Table 1. CCHS Disease Management Objectives to Help At-risk Patients

1. Become aware of patient problems.
2. Help patients understand and use the complicated healthcare system (i.e., identify social services for financial and transportation assistance, explain diagnostic services and genetic counseling, and offer resources to help with stress related to diagnosis and treatment).
3. Assist patients to understand diagnosis recommendations and treatment options.
4. Know the reasons for compliance with a mutually approved program.
5. Obtain needed referrals or second opinions.
6. Understand the pros and cons of clinical research trials when eligible, aided by specialty research nurses.
7. Understand when palliative treatments are needed to maintain a reasonable quality of life.
8. Encourage patients who have already gone through the diagnostic treatment and follow up activities to "buddy" with new patients when indicated. (This is an established program set up by the Psychology Department at CCHS.)
9. Help patients develop and keep their own medical records to use for unexpected consultation or when away. A new system of electronic records (CAPMED) is being piloted at the Helen F. Graham Cancer Center for patients to carry with them. Oncology nurse coordinators help patients store their medical histories on these storage capsules, such as memory sticks, for easy retrieval on any physician's computer.
10. Reduce healthcare costs, suffering, and deaths from cancer and its treatment complications.

Oncology Nurse Care Coordinators at Work: Two Case Studies

Patient 1

A 58-year-old woman presented with head and neck cancer. Her treatment called plan called for chemotherapy and radiation. The oncology nurse care coordinator assigned to this patient provided education regarding her disease and treatment and was responsible for coordinating the following services:

- Insertion of port catheter for chemotherapy and blood draws
- Insertion of PEG tube for administration of tube feedings
- Visit with registered dietitian to prevent weight loss
- Visit with health psychologist to talk about how to discuss patient's cancer diagnosis with family
- Visit rehabilitation department to address pain and rehabilitation concerns
- Coordination with Speech and Swallowing
- Transportation
- Financial Assistance
- Dental Consult
- Support Group
- Radiation Therapy
- Coordination and follow up with medical oncologist
- Follow-up calls through treatment to reassess patient and family needs.

Patient 2

A 45-year-old woman presented with breast cancer. Her treatment plan called for surgery, followed by chemotherapy and radiation. In addition to providing education regarding her disease and treatment, the oncology nurse care coordinator:

- Coordinated tissue procurement
- Assisted with prosthesis
- Provided social work support for the patient's family
- Linked the patient to a support group
- Provided information about various breast cancer community agencies to the patient
- Assisted with discharge planning needs (Patient was admitted to the hospital during her course of treatment.)
- Coordinated genetic risk assessment and counseling
- Helped set up the patient and her spouse in couples therapy
- Supported physicians and radiation therapy with treatment and follow-up
- Coordinated meeting with registered dietitian
- Follow-up calls throughout course of treatment to reassess patient and family needs.

Also participating in these conferences are research nurses, who actively educate physicians and other staff about clinical research trials that could potentially benefit cancer patients. A special clinical research meeting is held each month to discuss new studies and changes in protocols. At each meeting, a written report "scores" physicians on their accrual for that time period and year-to-date.

Accrual to approved clinical research trials has increased to 24 percent of new analytic cases. (This number compares to a national rate of 3 percent.) About 17 percent of MDC patients are accrued to research trials annually. Overall 643 cancer patients have been enrolled in 80 protocols of which 236 are treatment studies and 407 prevention and control research protocols. Since inception, more than 1,000 patients have been enrolled in the ELCAP Lung cancer screening program, with 17 percent enrolled in smoking cessation programs. More than 1,000 patients are on research follow-up routines.

Today, oncology nurse care coordinators work in tandem with medical, radiation, and surgical hospital staff, research staff, social workers, dietitians, and other supportive care staff, as well as private practice physicians, to deliver effective cancer care to all CCHS cancer patients.

Improving Cancer Disease Management

Because the oncology nurse care coordinator program is required to deliver a quarterly report card to the hospital's Cancer Committee, these nurses have become "experts" at developing and measuring performance improvement studies. Adhering to carefully planned objectives, the cancer center's oncology nurse care coordinators have improved many aspects of patient care and made the healthcare system more responsive to patient needs. For example, oncology care nurse coordinators have initiated more than 30 standing order sets by disease sites, including documentation tools and discharge instructions, for the MDCs (see Table 2, page 30).

Evaluation of the oncology nurse coordinator program itself is divided between quantifiable objectives (Tables 2 and 3, page 30) and less tangible elements related to increased patient satisfaction and improved services. While the latter tends to be more subjective and more difficult to measure numerically, the oncology nurse care coordinator program at the Helen F. Graham Cancer Center receives high marks from its patients. In a 2003 Patient Satisfaction Survey, the following items achieved a perfect score (5 out of 5):

1. Recommending the cancer program to others
2. [Patients] were treated with dignity and respect
3. [Patients'] privacy was respected
4. The staff helped with emotional concerns
5. [Patients] were overall satisfied
6. [Patients] were kept informed
7. [Patients] were aware of coordinator support
8. [Patients] were satisfied with instructions for home care and had responsive answers to questions.

In addition, the cancer center has received hundreds of letters from cancer patients supporting and praising the program's oncology nurse coordinators.

For more than three years now, the nurse oncology care coordinator program has been staffed by nine experienced oncology nurses. This dedicated, cohesive unit has helped thousands of cancer patients successfully navigate the CCHS healthcare system and receive state-of-the-art treatment and care. Oncology nurse care coordinators have also championed the MDCs, stimulating participation of patients in the multidisciplinary cancer care team consultation process.

Although they are not actually called patient naviga-

Table 2. Standardized Forms and Orders Developed by Oncology Nurse Care Coordinators

- Standardized medical history form developed and implemented in June 2003.
- Standardized pre-admission forms developed and implemented in 2004. These forms helped alleviate duplication and ensured information was shared among all providers.
- Standardized head and neck standing orders developed and implemented in February 2002 and revised in October 2003. The cancer center has since achieved 100 percent utilization by MDCs.
- Preliminary MDC treatment standards were made available in an electronic format in May 2002. Today, these standards are available to all staff via a Power Chart.
- Standardized hepato-biliary and pancreas standing orders developed and implemented in August 2002 and reviewed annually.
- Standardized patient discharge instructions for thoracic MDC developed and implemented in January 2003 and reviewed annually.
- Three admission craniotomy orders were replaced by one standardized order in February 2003. The order is reviewed annually.
- Standardized lung/esophageal standing orders developed and implemented by May 2003. Today, these orders are used for all lung and esophagus cancer patients.
- Developed one set of patient/family neuro-oncology surgical discharge instructions, which are reviewed annually.

Table 3. Performance Improvements Data Attributed at Least in Part to the Oncology Nurse Care Coordinator Program

- Developed and implemented a cancer care management assessment tool in October 2002. Currently, this tool is used for all new cancer patients.
- Developed a tumor conference algorithm to monitor compliance. The tool was put in place in March 2003 and is 92 percent compliant with NCCN guidelines.
- Ensured that 100 percent of Stage 3 colon cancer patients were referred for chemotherapy. (At the start of the oncology nurse care coordinator program, this referral rate was only at 47 percent. Within three months, referral was increased to 100 percent. It is now the responsibility of the GI oncology nurse care coordinator to ensure referrals are made.)
- Reduced average length of stay by 0.67 days per case.
- Documented a decrease in patients denied insurance coverage.
- Decreased time for diagnostic tests and operating room availability.
- Reduced waiting time for PET or bone scans from 2-3 weeks to 1 week.
- Reduced waiting time for CT/General X-rays from 1 week to 1 day.
- Increased referral of patients to Medicaid program. (In the last 9 months, 15 of 50 patients referred to Medicaid were approved.)
- Increased number of people screened by outreach staff. (In 2003, outreach staff screened 3,378 people.)
- Worked with the cancer research department to increase accrual to approved clinical research trials to 24 percent of new analytic cases
- Hosted 6 site visits from other cancer programs. These programs paid a fee to visit and review services at the Helen F. Graham Cancer Center.
- Helped procure special needs funds for more than 900 patients in a 4-year period for radiation and medical office visits, prosthetics, nutritional visits, genetic counseling, and medications.
- Increased the percent of cancer patients with moderate to severe pain who received pain consultations to 47 percent by December 2002.

tors, the oncology nurse care coordinators at the Helen F. Graham Cancer Center have indeed become excellent "navigators," and the glue that holds the CCHS healthcare system together from screening to terminal care, including diagnostic workups; medical, surgical, and radiotherapy treatments; follow-up routines for complications and recurrences; palliative care; survival; quality of life; and deaths.

While the benefits of nurse care coordination or "navigation" are inarguable, the final frontier for these providers will be to ensure that their services are reimbursed by payers. Currently, most of the services provided by CCHS oncology nurse care coordinators are *not* billable; however, these nurses do help generate downstream revenue in terms of tests and procedures that are reimbursed, including genetic counseling, registered dietitian services, and visits with health psychologists and physicians. In addition, CCHS credits its oncology nurse care coordinators with helping decrease patient length of stay—a move that is good for patients, payers, and providers. Until that time, the Helen F. Graham Cancer Center remains committed to seeing that *all* cancer patients continue to benefit from its oncology nurse care coordinator program—regardless of whether these services are paid.

References

[1]Anderson SL. *Reasons for and Experiences with Oncology Nurse Cancer Care Management*. A presentation to: The President's Cancer Panel, May 24-25, 2001; Washington D.C.

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