

# Thoracic Oncology Patient Navigation

## Creating a site-specific navigation program

by Susan Abbinanti, MS, PA-C

*When you are diagnosed with lung cancer, there are many procedures you need to have to establish a comprehensive diagnosis. The patient navigator takes the burden off the patient to get those tests and procedures scheduled. They are an important link between the doctor, the patient, and all other adjunct services. Perhaps most importantly, patient navigators are the 'constant' in the continuum of care to return the patient to wellness. They offer patients a personal contact to help alleviate their fears and concerns.*

—Patti Jamieson-Baker, MBA  
Vice President  
The Cancer Institute at  
Alexian Brothers Hospital Network

**T**he evaluation and management of lung cancer can be complex. The majority of lung cancer cases are diagnosed at an advanced stage, with treatment often involving intensive multi-modality therapies. So in 2006, Alexian Brothers Hospital Network, which includes a 400-bed community hospital comprehensive cancer program and a nearby 331-bed community hospital cancer program in northwest suburban Chicago, began offering lung cancer patient navigation services. Here's how the site-specific program was developed and implemented.

### Thoracic Oncology Coordinator

Under the direction of a newly hired dedicated thoracic surgeon, Alexian Brothers initiated a formal thoracic oncology program in 2006. The thoracic oncology program included a newly created FTE patient navigator position. Because the navigator would provide care to *all* thoracic oncology patients—not just lung cancer patients—the job title for the new position was thoracic oncology coordinator. The decision was made to hire a mid-level provider from outside the hospital system for this newly created position. Because the new coordinator had no prior relationships within the hospital network, the individual could be perceived as an

objective staff member who would be an advocate for the patients and the thoracic oncology program—rather than any specific agenda or physician group(s). An initial period during which physicians would need to develop a level of trust in the new coordinator's abilities was anticipated.

The thoracic oncology coordinator is a hospital network employee based at The Cancer Institute at Alexian Brothers Hospital Network. Navigation services provided by the thoracic oncology coordinator are loosely modeled after Alexian Brothers' breast navigation program, which has been in operation since 2000. In a similar fashion, the thoracic oncology coordinator provides support and education for thoracic oncology patients and their families at the time of diagnosis, during treatment, and beyond. Specific duties include:

- Planning multidisciplinary conferences
- Acting as a liaison between members of the care team
- Tracking programmatic quality indicators
- Networking with community organizations
- Providing community education.

In the present healthcare system, patient navigation services are gener-

ally non-billable. Therefore, administrative support and understanding of the patient navigator's role is crucial. At Alexian Brothers, we believe that patient navigation helps improve patient outcomes and satisfaction, which translates to more patients choosing to remain within our hospital system for care. This, in turn, increases downstream revenue for our hospital.

Navigation services can also be attractive to referring physicians. Today, physicians are often on staff at multiple hospitals. Ensuring that primary care physicians are aware of the quality care that their thoracic oncology patients receive from our thoracic oncology coordinator can potentially help grow patient volumes.

### Culture Counts

The culture of the institution is a key factor in developing a workable thoracic oncology navigation program. Planning for our program included investigating multiple navigation models and a site visit to a well-established lung cancer patient navigation program at St. Joseph Hospital in Orange County, California, to observe a best practice model in operation. During our literature search we identified one navigation model that referred suspected or newly diagnosed lung cancer patients to a call center where a patient coordinator or navigator scheduled tests and specialty physician appointments. Given that both Alexian Brothers Medical Center and St. Alexius Medical Center are community hospitals with patients coming into the system from multiple on- and off-site private physician offices with well-established referral patterns, the call center model was not viewed as a good fit.

Many primary care physicians refer patients with suspected lung cancers to a pulmonologist for further evaluation, but a significant number will either send the patient to a surgeon or direct the diagnostic workup themselves. Under our model, the thoracic oncology coordinator is

available to all physicians' offices and patients to assist with scheduling diagnostic tests; however, the pattern that naturally developed in our hospital network was for the thoracic oncology coordinator to meet most patients after diagnosis.

That said, given the multiple points of entry into our healthcare system, meeting all lung cancer patients can be challenging for our thoracic oncology coordinator. Some third-party payers require that the diagnostic workup be done as an outpatient, and sometimes even at multiple locations. If the patient has metastatic disease, he or she may be referred from the primary care physician's office directly to an off-campus oncologist. When the oncologist's office is off-site, the thoracic oncology coordinator may initially contact the patient by phone. The patient is then met in person at a later time when he or she is at the hospital for a scheduled test.

### Patient Benefits

Our thoracic oncology navigation program has benefited patients in several ways. Patient education, psychosocial support, and advocacy services are some of the key functions of our thoracic oncology coordinator.

**Education.** We collect educational and supportive materials at no cost from multiple sources, including national lung cancer organizations and pharmaceutical companies. The thoracic oncology coordinator individualizes these materials on a case-by-case basis. Educational and supportive materials are then either mailed to the patient's home or delivered to the office of a physician on the patient's treatment team. Lung cancer patients typically express dismay at the prognostic statistics they read in books or on the



**Multidisciplinary lung cancer conferences are an integral component of the thoracic oncology program at Alexian Brothers Hospital Network.**

Internet, and often limit their exposure to information afterward. In response to patient feedback, our lung-cancer-specific booklets are concise, with more comprehensive printed material provided upon request.

Families and significant others can benefit from receiving written information on strategies for being supportive to someone with a cancer diagnosis. At the same time, well-meaning family and friends often research multiple treatment options, many which make claims that are not evidence-based. The thoracic oncology coordinator is available to provide individualized emotional and educational support for patients and their families in an objective and understandable fashion.

**Psychosocial support and advocacy.** Receiving a diagnosis of lung cancer can be a frightening and confusing time for patients and their families. The availability of information on the Internet can be overwhelming. If the patient is a current or former smoker, an added component of guilt can affect not only the patient's willingness to be treated, but family support as well.<sup>1</sup>

Frequently, patients ask our thoracic oncology coordinator to simply provide hope. Both hospitals within the Alexian Network offer lung cancer support groups, and the thoracic oncology coordinator plans and attends all of these meetings. The groups meet monthly and often feature speakers on various topics

of interest. Two of the most popular topics are complementary medicine and physician question-and-answer sessions. For patients who are not comfortable in a group setting, the thoracic oncology coordinator can connect them with another patient in a similar situation who has already gone through treatment and volunteered to be available for one-on-one support. During Lung Cancer Awareness month in November, all lung cancer patients are invited to a lung cancer survivors' luncheon. Some of the same patients have returned for several years, providing hope and encouragement to others.

When appropriate, the thoracic oncology coordinator refers patients and family members to other support services, such as nutrition or social work.

**Scheduling assistance.** For lung cancer patients, traveling long distances to a tertiary care center for chemotherapy or daily radiation therapy treatments can be a hardship. The median age at diagnosis for lung cancer patients is 71 years.<sup>2</sup> Many patients have significant co-morbidities and transportation issues. Most patients express a desire to receive treatment for lung cancer close to home, where their primary care physician can remain involved.

At the urging of family, newly diagnosed lung cancer patients often seek a second opinion at an academic institution. A thoracic oncology coordinator can support the patient

and family in their desire to be seen at another medical facility and can help gather the necessary medical records. If the recommended treatments are the same at both institutions, the majority of lung cancer patients opt to receive their treatment locally. The thoracic oncology coordinator is often involved in supporting the patient through this decision.

### Programmatic Benefits

Thoracic oncology navigation services also offer a number of programmatic benefits: 1) expediting the diagnostic workup and start of treatment; 2) improving patient participation in clinical trials; and 3) increasing patient volumes. Other programmatic benefits include:

**Multidisciplinary lung cancer conferences.** These conferences are an integral component of our thoracic oncology program. The thoracic oncology coordinator participates in case selection, helping prioritize cases if the agenda is full. The thoracic oncology coordinator prepares a concise, comprehensive case summary to assure that the physicians attending the multidisciplinary conferences have all the necessary information to discuss the case. As physicians become more aware of lung cancer patient treatment options, nihilism does not appear as prevalent. One of the goals of the thoracic oncology program is to increase the number of cases discussed prospectively.

Accurate staging is key to optimal lung cancer management. To date, our outcomes measurements have focused on increasing physician awareness and compliance with national guidelines so as to standardize the evaluation and management of thoracic malignancies. We evaluate each patient case for adherence to national guidelines in diagnostic evaluation and treatment planning. Referring physicians can now expect that their lung cancer patients are managed according to a uniform set of guidelines.

When areas for improvement have been identified, physician support has been excellent because our quality improvement activities are evidence-based and supported by the hospital's Cancer Committee.

**State-of-the-art technology and treatment.** Another priority of the thoracic oncology program is being able to offer lung cancer patients the latest technology. Our thoracic oncology coordinator is knowledgeable about cutting-edge treatments and able to provide the most accurate and up-to-date information to patients and families. For example, the thoracic oncology coordinator often attends product demonstrations and/or observes the delivery of new technologies to stay abreast of new technologic and treatment advances. Our thoracic oncology coordinator also communicates with staff physicians regarding new technology-based treatments gleaned from peer-reviewed literature or at professional conferences.

### Spreading the Word

There was an early focus on internal and external marketing of our lung cancer navigation services. Internal marketing included articles in physician newsletters, lunch-and-learn presentation in physicians' offices, and participation in hospital CME activities, such as grand rounds. External marketing included exposure in local publications, speaking to community groups, and involvement with community respiratory organizations. Patient and family word of mouth and comments on the Internet are under-recognized but powerful motivators.

Lung cancer is not a "sexy" topic by any means. A lot of stigma is still associated with lung cancer. Raising community awareness is important both from the standpoint of educating the public about signs and symptoms of lung cancer as well as programs that support lung cancer patients and research funding. The thoracic oncology coordinator helps increase community

awareness about lung cancer in general and the hospital network's thoracic oncology program specifically by:

- Participating in local walks or hikes
- Planning performances and benefits by artists who desire to help raise awareness and funds
- Accepting speaking engagements at local civic organizations
- Networking with other thoracic oncology coordinators to foster the exchange of information and strategies used by other programs.

In 2007 about 20 navigators and nurse coordinators attended the first regional thoracic oncology conference for navigators and coordinators. Spearheaded by Michele O'Brien, a thoracic oncology CNS, the meeting focused on developing the nurse coordinator role in thoracic oncology. It has now become an annual event.

While navigation services are considered an important aspect of comprehensive cancer care, programmatic benefits need to be measurable. To that end, Alexian Brothers purchased and implemented a thoracic oncology database. It is anticipated that the information gleaned from this database will help us identify strengths and weaknesses that will help in developing program goals, without duplication of statistics generated by the cancer registry. ✓

*Susan Abbinanti, MS, PA-C, is thoracic oncology coordinator at The Cancer Institute at Alexian Brothers Hospital Network in Elk Grove Village and Hoffman Estates, Ill.*

### References

<sup>1</sup>Dvorak P. Lung cancer's double burden. *Washington Post*. January 20, 2009. Available online at: [http://www.washingtonpost.com/wp-dyn/content/article/2008/12/12/AR2008121203425\\_pf.html](http://www.washingtonpost.com/wp-dyn/content/article/2008/12/12/AR2008121203425_pf.html). Last accessed March 10, 2009.

<sup>2</sup>National Cancer Institute. SEER Stat Fact Sheets, Cancer: Lung and Bronchus. Available online at: <http://seer.cancer.gov/statfacts/html/lungb.html>. Last accessed March 10, 2009.