## **Cancer Care Patient Navigation**

A practical guide for community cancer centers



A Publication of the Association of Community Cancer Centers

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### **Patient Navigation: A Call to Action**

by Virginia T. Vaitones, MSW, OSW-C

entral to ACCC's mission is ensuring timely patient access to appropriate cancer care. Over the past decade, patient navigation services have been emerging as an important strategy for enhancing patient access to the full continuum of cancer care from screening to detection, diagnosis, treatment, and beyond.

ACCC's Patient Navigation: A Call to Action project is designed to help community cancer programs establish or expand patient navigation services. Included in this supplement is the newly developed Patient Navigation guideline from ACCC's Cancer Program Guidelines. To view ACCC's full Cancer Program Guidelines go to www.accc-cancer.org.

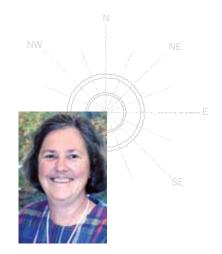
This supplement is not designed as a "how to" guide. It is a resource for community cancer programs interested in implementing or expanding patient navigation services. We've included articles describing five model patient navigation efforts currently underway at ACCC member programs. The range in program design and scope demonstrates that there is no one-size-fits-all template for patient navigation programs. Rather, these services can be designed to dovetail with your program's specific resources, community needs, and strategic objectives.

Included are sample tools from successful navigation programs, such as pre-assessment forms, intake summaries and referral forms, navigation tracking forms and progress notes, patient satisfaction surveys, and outcomes measures.

And, we've included an interview with Dr. Harold Freeman, who in 1990 first conceived and developed a patient navigator service to help underserved populations access the healthcare system. Dr. Freeman talks about what he believes is essential to any patient navigation program. He also describes the Harold P. Freeman Patient Navigation Institute, founded in 2008, to help define patient navigation, create standards, and develop a certification process for people who were trained in the patient navigation program concept.

As the model programs in this supplement demonstrate, patient navigation in community cancer centers can be tailored to meet the unique needs of the community, patients, and caregivers. Patient navigation services can streamline patient access to care, enhance quality care, and increase both patient and provider satisfaction.

With more than 30 years of experience as an oncology social worker, Virginia T. Vaitones, MSW, OSW-C, has also been an active participant and supporter of ACCC, serving on the Association's Board of Trustees, and ACCC's Program, Guidelines, and Patient Advocacy Committees.



## Association of Community Cancer Centers Cancer Program Guidelines

#### **Chapter 4: Clinical Management and Supportive Care Services**



#### SECTION 10

#### **Patient Navigation Services**

#### Guideline I

A patient navigation program is available for patients, their families, and caregivers to help "overcome health care system barriers and facilitate timely access to quality medical and psychosocial care from pre-diagnosis through all phases of the cancer experience." \*

#### Rationale

The diagnosis and treatment of cancer and living with the disease may be confusing, intimidating, and overwhelming for an individual, family member, or caregiver. Cancer programs have a responsibility to assist our patients, their families, and caregivers to navigate the continuum of care through a navigation program developed by the cancer program or via a partnership with a community agency that utilizes patient navigators. Since each cancer program understands its unique patient

population and its community, individual programs or health systems can best create a navigator system that suits its needs.

#### Characteristics

- A. Patient navigation may include but is not limited to oncology social worker(s) and nurse(s) who may:
  - Act as a coordinator to ensure the patient, their family members, and caregivers move through the complexities of the system in a timely fashion
  - Provide psychosocial services to patients, families, and caregivers or refer to oncology social worker for psychosocial care
  - 3. Link patients, families, and caregivers with appropriate community resources (i.e., financial, transportation, translation services, and hospice)
  - Provide education to the patient, families, and caregivers throughout the continuum of care
  - Link patients, families, and caregivers with appropriate post-treatment follow-up care.
- B. Trained volunteers and non-clinical paid staff may provide some of the navigator activities and functions under defined conditions and with professional oversight.
  - Cancer programs may choose to select, train, and oversee their own volunteers or nonclinical paid staff.

- Cancer programs may choose to partner with an organization that employs patient navigators or uses volunteers.
  - a) The cancer program will help determine who will oversee these navigators.
  - b) The cancer program will develop a contract between the navigator(s) and the program that clearly outlines the role the navigator(s) will have with patients and families.
  - c) The cancer program will develop an orientation and training program that the navigators must attend.
  - d) The cancer program will provide an ongoing in-service education program for the navigators.
- 3. The program should provide adequate space for confidential interviews and counseling.
- Navigators should receive training in ethnic, cultural, and religious diversity as well as ethics.
- Mechanisms exist, when necessary, to review the plans and coordinate among team members.
- Navigators should facilitate communication between patient and providers.
- Navigators should educate the oncology staff about the navigator program and how it will be integrated into the oncology program.

<sup>\*</sup>From a definition created by C-Change, May 20, 2005. Permission granted. "Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care from pre-diagnosis through all phases of the cancer experience."

### A Conversation with Dr. Harold P. Freeman

#### An Interview with Amanda Patton, Associate Editor, ACCC

Harold P. Freeman, MD, is an internationally recognized authority on the interrelationships between race, poverty, and cancer. In 2007 the Harold P. Freeman Patient Navigation Institute was established to set and ensure standards for patient navigation programs through an emphasis on the navigation model developed by Dr. Freeman. In an interview, Dr. Freeman shares his perspective on why patient navigation remains a critical need in cancer care.

## Q. Why do you think the use of patient navigators is becoming more prevalent?

Patient navigation is an important concept. The American healthcare system is fragmented. Many Americans, especially the poor and uninsured, meet barriers to receiving timely diagnosis and treatment of cancer. Patient navigation programs are becoming more prevalent because patient navigators serve to eliminate barriers to timely diagnosis and treatment.

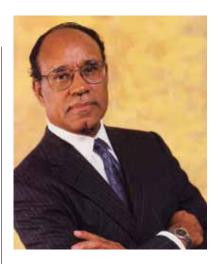
Secondly, I think the larger issue is that there are an estimated 45 million uninsured in America and an additional 25 million American citizens who are underinsured and, therefore, may not be able to pay for treatment. Healthcare is the number one cause of bankruptcy in America.

And thirdly, if you look at 32 million American people on Medicaid, a study published just a few months ago by the American Cancer Society showed that people on Medicaid have no better cancer outcome as measured by survival and mortality compared to people that are uninsured. So when you put together the 45 million uninsured, the 25 million underinsured, and add the 32 million on Medicaid—just those categories alone add up to 100 million people who are likely to have severe challenges when they attempt to enter the healthcare system. That's one-third of the American people.

The problem is very large and the issue is that in communities these people who have these barriers must fight their way through the system. Often they become disillusioned and give up hope. So if there is a strategy which eliminates barriers for people who don't have the knowledge or the resources or insurance—if there's a way to create a program which causes these people to move rapidly through the system to earlier diagnosis and full treatment—then this is the reason that patient navigation seems to be working and catching on.

# Q. In 1990 you developed the patient navigation model in an effort to remove the barriers you've just described. Do you see the primary mission of navigation still to be to address these problems?

A. I truly believe that navigation may benefit people of all socio-economic statuses, but it's most important for people who don't have the resources and the knowledge [about cancer detection and treatment] and that should be the target audience. However, as we learn more, we are finding that there are people who meet barriers who are insured or who do have knowledge [about cancer detection and treatment). I think it's a broader issue that needs to be applied to the whole population of people who either develop cancer or are in the process of being diagnosed for cancer. I think that the critical part and the most effective and the most necessary part—of navigation is to target it to populations that are underserved or less educated or uninsured.



But I do believe patient navigation has a universal benefit for all patients and is even being applied to diseases other than cancer.

## Q. In January 2008 the Harold P. Freeman Patient Navigation Institute was launched. What was the impetus for the Institute?

A. By this time navigation had begun to spread rather rapidly to different sites throughout the country.... First of all starting with the United States government, the NCI has funded 9 patient navigation programs starting about 5 years ago, demonstration sites. The Centers for Medicare & Medicaid Services (CMS) has funded 6 patient navigation sites, which is very important because CMS oversees Medicaid and Medicare. And thirdly, most recently, HRSA [Health Resources and Services Administration] has 6 sites. In 2005 the Patient Navigation Act, based on the model in Harlem, was signed into law by President George Bush.

In the meantime, the number of agencies and nonprofits supporting patient navigation, such as the American Cancer Society, the Susan G. Komen Foundation, the Avon Foundation, have rapidly increased around the country.

So while hundreds of patient navigation sites were developed, there were no clear standards or definitions for what patient navigation is. In other

## ...the navigator's job is to see the entire movement of the patient across disciplines.

words, the term patient navigation is being used in many ways. We saw the need to try to create some standards of patient navigation that people could at least compare to or with the hundreds of sites that were developing. And these sites were developing in very different ways throughout the country—sometimes concentrating on other elements such as diagnosis and/or treatment.

We saw the need for creating an institute that could define patient navigation and create standards and a certification process for people who were trained in the patient navigation program concept as it was developed in 1990 and which we now have 19 years experience with. And that was the impetus for the creation of the Patient Navigation Institute which has been funded by a leadership grant from the Amgen Foundation.

## Q. What are the goals of the Institute?

A. There are two goals: One is to set and ensure standards for patient navigation programs through an emphasis on the Patient Navigation Model that I initiated in 1990. A second goal is to help others learn best patient navigation practices by creating a national database for the collection, analysis, and dissemination of information on best navigation practices.

## Q. Can you briefly describe the Institute's navigation training program?

A. It's a three-day training course that we give usually once a month. We have developed training modules for the course. I generally start off the course with an Introduction Module about the origins and evolution of patient navigation. Then we have a module on how to create a patient navigation program; a module related to cultural sensitivity and cultural issues; and a module on the

[patient navigation] database—how it's been formed, and suggestions for how participants can create their own database.

Part of the training is done with our navigators at the Ralph Lauren Center. We have developed a program in which navigation is carried out by four navigators each of whom is responsible for a particular phase of navigation:

- 1) Outreach navigator
- 2) Diagnostic navigator
- 3) Treatment navigator
- 4) Financial navigator.

These navigators are in close communication with each other in the management of a given patient.

For the Institute's training program, all of these navigators come in and talk about their role in patient navigation. The idea is that there is a continuity that should take place for patients. It begins in the community where they live to get them into the center where the test is done—that's called outreach navigation. Then, at the point of an abnormal finding, the diagnostic navigator takes the patient through the point of diagnosis and the finding of cancer or no cancer. At this point, we have a treatment navigator to work with the patient through all the forms of treatment. And finally, as a sort of consultant to these navigators is a financial navigator whose work is to make sure that the patient has financial coverage.

## Q. How many navigators have been trained to date?

A. Since we started the first Navigation Training Course in January 2008, we have trained 181 navigators from 85 institutions in 33 states, including Alaska and Hawaii. In addition, some trainees have come from the Caribbean and parts of Europe.

## Q. And the Institute is still accepting applications?

A. Yes. We encourage people to apply and they can apply through our website (www.hpfreemanpni.org). The course gives the total picture of how patient navigation developed, and, with this much experience, we've developed navigation to a pretty sophisticated level at this point.

One thing to point out is that the concept of navigation has to do with addressing the entire continuity and movement of the patient through the system from the community to the healthcare site and ensuring that patients get the tests they need, such as a mammogram, to ensure that any abnormal findings will be rapidly resolved. Timeliness is a very critical part of navigation. And then to assure that anyone who has cancer will get rapidly treated by all modalities.

So navigation encompasses the concept of continuity from the community to the healthcare setting to getting the test, having the finding, and getting the patient all the way through treatment. Now the navigator in our concept is the only person in the healthcare system whose job it is to watch and guide and assist the patient through this entire continuum. In other words, the navigator's job is to see the entire movement of the patient across disciplines. One of the problems in medicine is that we have excellent areas—excellent surgeons, excellent radiation departments—but the patient doesn't easily pass through one part into another. So we are working across disciplines that have to be bridged through this navigation.

## Q. So the training provided at the Institute can help bridge these challenges?

A. Yes. We've found that the four principal barriers patients face are:

- Financial barriers—no insurance or not enough insurance, or lack of ability to pay for transportation, and other costs related to cancer care.
- 2. Communication barriers—people

### ...if navigation is going to be cost-effective, part of it can be done by lay navigators who are not clinical professionals.

- don't really understand the medical information that's been communicated to them.
- Complexity of the healthcare system—when people have to move from a surgeon who says you need a biopsy to medical clearance and then back again, or from surgery to chemotherapy—they get lost in the system
- 4. Barriers related to fear and distrust and emotional issues.

Our navigators work with all of these barriers. While we use lay navigators as the principle navigators in our system, we realize that there's a role for navigators who are professionals, especially social workers and nurses, to navigate people at more complex points. For example, if the lay navigator finds that the person is experiencing social problems...then that navigator will refer the patient to the social worker. Or when patients with cancer have challenges with respect to understanding the disease and the options for treatment, the navigator will call in a nurse or an oncology nurse to navigate those issues.

But we find that the trained lay navigator can eliminate many barriers faced, particularly in poor communities. These barriers include: lack of medical insurance, under insurance, and how to obtain various medical and support services.

We believe there should be an interconnection between the lay navigator and the professionally trained navigator, such as a nurse or social worker, and that they should be working together to move the patient through the treatment of cancer. This approach is also cost-effective in that highly trained healthcare professionals are not spending time on work that can be handled by non-clinical staff members, such as a lay navigator.

I know there's been debate about the use of lay navigators versus the use of clinical navigators, but I think we need to work together on who should navigate. I don't like the idea of any

single group of people arguing that they "own" navigation because that's simply not correct. There is room for all kinds of people to be navigators. And certainly, if navigation is going to be cost-effective, part of it can be done by lay navigators who are not clinical professionals. We should concentrate on what has to be done for the patient as opposed to what we want to do in our specialty. And if we do that, we soon come to the realization that everybody has a role in navigation. From the lay person, the nurse, the social worker all the way through to administration, it's a team effort with everyone having their eyes on what has to be done for the patient as opposed to turf issues.

We should embrace the philosophy that navigation is a continuum of actions that need to be carried out for our patients, and that at certain levels these actions are relatively simple and can be done by a lay navigator, but as cancer treatment becomes more complex in terms of social services or clinical services, a clinically trained navigator should step in. It's important that the navigation system is set up so that the entire healthcare institution will embrace this as an idea so that the team can really work together rather than have conflicts over turf.

## Q. From your patient navigation database do you have any emerging best practice information you can share?

We are finding is that in sites around the country people are concentrating on segments of the navigation problem, working with the screening part of navigation for example. The concept we're teaching is that you have to initiate the navigation at some point, whatever your definition is for when that starts, and then you have got to finish the navigation. Close the case. The case isn't over until it's over. In other words if you have an abnormal finding, you have to resolve this through diagnosis. And

if it's cancer, it has to resolve with the treatment of cancer.

We're getting the sense from talking to people around the country that people are working on segments of the navigation problem without the full continuum of care in mind. If you have cancer, it's not over for you until the cancer has been treated. We're seeing navigators that do parts of navigation very effectively, but we are teaching at the Institute that while it's okay to do whatever your part is, we also have an obligation to connect the whole system for the patient. So that's a very important navigation concept: to open the case and to define when your navigation begins and to close the case and define when your navigation ends. We believe, in cancer care, navigation should end at the end of treatment.

And we have to develop survivorship navigation support systems for survivors who have recurrent disease of special areas that need to be addressed through special training. What I see is that navigators in various sites around the country are taking on parts of the navigation process and not necessarily connecting to the next action that needs to be done for the patient. And to use an analogy from surgery, it's not over until you close the case.

#### Q. Some programs begin navigation services with a single disease site, such as breast cancer. Is it your sense that this is a good way for programs to begin to work with navigation services?

A. I think that is generally the way it has been happening. My wish is that navigation programs will cover all cancers. We would like to encourage institutions to navigate all cancer patients. It would be better for society if patient navigation programs were made available to eliminate barriers to diagnosis and treatment of all cancers, as well as to other chronic diseases such as diabetes, heart disease, and psychiatric and neurological conditions. ✓

## Patient Navigation Program Pre-Assessment Tool



This pre-assessment tool can help you assess your organization and consider all aspects of a patient navigation program. This tool can also help you assess your readiness for implementation or identify areas that need to be addressed before rolling out a patient navigation program.

G	DALS AND CHALLENGES
1.	Goals for navigation program:
2.	Barriers/Challenges to navigation program:
0	PERATIONS
1.	Tumor types to be covered by navigation program:
2.	Will each tumor type have its own navigation program or will one navigator cover more than one tumor type?
3.	Do you have team(s) to set up program(s) by disease state(s)?
4.	Timeline for implementation:
5.	How many patients per year will participate in the navigation program?
6.	What is your anticipated patient to navigator ratio?
7.	How will you identify patients eligible for the program? ☐ Pathology reports ☐ Inpatients ☐ MD referrals ☐ Surgical reports Other
8.	What are the biggest challenges facing the patient that need to be addressed by the navigation program?
9.	Where will the navigator(s) be housed?
10	What other space is allocated for the navigation program:  ☐ Patient library/education space  ☐ Counseling rooms  ☐ Other offices
11.	How will program be funded? ☐ Grants ☐ Patient pays ☐ Insurance

13. Which salaries will be supported solely by program budget (navigator, administrative assistant, etc.)?

ACCC'S CANCER CARE PATIENT NAVIGATION: A CALL TO ACTION

12. Will patients be charged for any part of the service?

14.	Which salaries will be partially supported by program budget (social work, PT/OT, etc.)?								
15.	5. What else will budget be used for (patient education materials, journals, etc.)?								
16.	6. Do you have an electronic charting system?								
17.	How will you communicate between practitioners?								
RO	DLE OF NAVIGATOR								
18.	Who do you see as the navigator in your program?  ☐ RN ☐ Social Worker ☐ Lay person/survivor  Other								
19.	When would you like the navigator to become involved with the patient?  Prior to entering the healthcare system At time of suspicious finding Other (please specify)								
20.	What are the primary functions you would like the navigator to fulfill? Please rank them with 1 being the most important. Community educationPatient educationCare coordinatorFinancial counselorPsychosocial counselorOther (please specify)								
21.	What other activities would you like the navigator to be involved in? Please rank them with 1 being the most important. QI/PI activitiesCommunityEducational programsScreeningsStaff educational programsSurvivorship programHelp set up program(s) by disease state(s)Other (please specify)								
RE	SOURCES								
22.	What resources do you currently have in place?  Case managers  Genetic counselors  Chaplain  Health psychologists  PT/OT  Speech therapy  Home care services  PT/OT Patient advisory committee  Support groups (specify)  Other (please specify)								
23.	Do you currently have relationships with community patient support agencies such as ACS or local support groups other than hospital-based groups?								
ОТ	THER CONSIDERATIONS								
24.	Do you have an MD champion for patient navigation program?								
25.	Do MDs support the program? If not, will MDs need convincing of the need for a program?								
26.	Administration level support/commitment or lack of support/commitment?								
27.	What percentage of your population has?  Private health insurance  Medicare  Medicaid  No insurance								
28.	What percentage of your population is?  African American Asian Caucasian Hispanic Native American Other (please specify)								

## Patient Navigation: A Multidisciplinary Team Approach

by David Nicewonger, MHA

MultiCare Health System is a community-based healthcare organization based in Tacoma, Washington, that includes four hospitals, a multidiscipline physician group, and various other service lines. MultiCare Regional Cancer Center (MRCC) is a hospital-based oncology practice consisting of five medical oncology practices and two radiation oncology practices.

In 2005 MultiCare entered into a five-vear strategic planning process for cancer services. At that time the services delivered included basic oncology services with very little structure beyond physician, infusion, and radiation services. Data gathered through a survey of patients and families revealed a significant unmet need related to the support patients received throughout their treatments. Likewise, a survey of staff at that time showed considerable frustration expressed over a lack of resources to provide patients with much needed support beyond basic cancer treatment. Based on this survey data and as part of the strategic planning process, we decided that future programs would build on four fundamental foundations:

- 1. Facilities
- 2. Providers
- 3. Technology
- 4. Patient support systems.

#### **Putting the Team to Work**

The strategic plan ultimately approved by MultiCare's Board of Directors included the development of a Patient Navigation Team. This team would be charged with addressing the unmet needs identified by patients and their families. By early 2006, patient navigator job descriptions were developed and the first members of the Navigation Team were hired.

MultiCare Regional Cancer Center (MRCC) developed the concept and structure of its Navigation Team by drilling into the details of the patient and staff surveys. The most commonly identified needs were then bundled into four categories:

- 1. Care management and coordination
- 2. Social and psychosocial support
- 3. Financial support and counseling
- 4. Nutritional support and education.

While multiple needs and issues existed within each of these four categories, these fundamental patient needs drove the decision to create a multidisciplinary Navigation Team versus the traditional pool of case managers. By leveraging the focused skills of each individual on the team, we believed that cancer patients would be better supported and that team members would be more satisfied with their work.

The first three members of MRCC's Navigation Team were an RN navigator, a social worker, and a patient representative who provided financial assistance. While we initially requested a larger Navigation Team, the model was untested and hospital leadership initially approved the smaller threeperson team. This approval came with the expectation that Cancer Center leadership would return in one year to report on outcomes and conclusions regarding continuation or expansion of the navigation program. Specific outcomes measures were identified, including improved patient satisfaction and increased patient volumes for the Cancer Center.

#### **Growing the Team**

MRCC's Navigation Team initially focused on helping patients through the

first weeks of their cancer treatment. The team's motto: "Patients and families should only have to focus on healing." The Team's goal: to take all of the peripheral worries out of their patients and families hands.

One of the Navigation Team's first tasks was to conduct another survey of new patients to obtain a baseline score measuring how well supported patients felt *before* the Team started its work (see Figure 1, page S12-13). The results of that survey became the defining structure for the Navigation Team's work, and over the course of the first year, the survey was repeated for new patients entering the program.

By the end of that first year, MRCC saw significant improvements in all but two areas: assistance making and/or getting appointments with other MultiCare departments and transportation issues. Furthermore, physicians in the clinic and nurses in the infusion centers reported that the Navigation Team allowed them to focus on direct patient care rather than struggling with how to address issues such as transportation or financial coverage. The Navigation Team also maintained a log of patient stories, documenting successful interventions and the impact on the lives of patients entering cancer treatment.

At the end of the first year, hospital and cancer center leadership looked at these findings and approved the addition of three new team members: a second RN navigator, a second patient representative, and a nutritionist. The expanded Patient Navigation Team supported all patients who received care at MRCC's main campus but another ongoing challenge remained: how could the Navigation Team support staff and patients at satellite clinics where patient volumes were significantly lower but needs were just as important?

To help initially address this challenge, we adopted a model that combined the job functions of the RN navigator with a clinic supervisor. In small clinical operations, where the supervisory demands are less signifi-

# cant, this approach provided some navigation support for the patients. Later, an organizational focus on standardization of care across all care locations led to the approval of an additional social worker and patient representative in the

#### Disease-site-specific Navigators

next budget cycle. The expanded eight-

person Navigation Team was then able

to service all clinical locations.

Another component of the original strategic plan was a focus on four primary disease groups: 1) thoracic, 2) urologic, 3) breast, and 4) neurologic. While our cancer program treats all cancer types, the decision was made to focus on these primary disease groups with the eventual goal of becoming a center of excellence in those areas. Over time it was acknowledged that this goal would be best achieved by having disease-site-specific navigators. And while the general navigators continued to function in the clinics, these new disease-focused navigators became a key component in MRCC's strategy to develop a program of excellence for each disease site.

The disease-site-specific navigators were expected to work not only with the patient and family, but also to serve as a direct liaison between the cancer program and referring physicians and surgeons. Our expectation was that navigator services would be valued by both patients and referring physicians; therefore, providers would be more likely to direct their patients to a Multi-Care facility. Accordingly, we projected substantial volume increases in cancer services during our 2008 budget planning process.

So, in addition to the two general RN navigators, our Navigation Team would now include four disease-site-specific navigators. While three of the disease-site-specific navigators would be RNs with an oncology background, we decided to fill the other position with an ARNP who could provide service at a different level. Under this model, the ARNP navigator provides

### **9 Ways Patient Navigation Can Benefit Your Cancer Patients**

- Patient navigators become the initial contact point for all patients who come into contact with the healthcare system. They remain an ongoing, consistent point of contact for patients and families through the full continuum of their care
- 2. Patient navigators support patients as they move through different points of the healthcare system, including hand-offs between inpatient and outpatient settings, specialty consultations, research, hospice, and/or palliative care. Smoother hand-offs across all phases of care translate into fewer delays in treatment, improved communication between caregivers, and less confusion for the patient and family.
- 3. Patient navigators provide valuable education to patients and families on a variety of treatment, nutritional, financial, or social issues.
- Patient navigators can help decrease ER visits associated with complications in care by identifying complications sooner and directing earlier interventions at the clinical level.
- Patient navigators link patients and families to community resources such as transportation, housing assistance, financial assistance, and/or support groups.
- 6. Patient navigators optimize access to financial resources to assist patients and families with treatment-related costs, including drugs. This access is particularly critical for indigent, uninsured, and under-insured patients.
- 7. Patient navigators offer emotional support to patients and families during difficult and stressful times.
- 8. Patient navigators can help match patients to potential research protocols.
- 9. Patient navigators can provide a valuable link between the cancer center and the community physicians referring into the cancer center.



MultiCare Regional Cancer Center's multidisciplinary Navigation Team.

some direct patient care and works directly with community physicians and surgeons to provide support and intervention on cases earlier—often before the patient even enters the actual oncology clinics. Some of the services performed by our ARNP navigator, such as office visits for ongoing care, are billable. And while the billable charges do not fully support the ARNP salary, the additional revenue stream is enough to make up for the difference between the salary of an ARNP versus

using an RN in the same position. With an ARNP navigator, the level of connection and collaboration with surgeons is enhanced. Again, our assumption is that improving those relationships and making the navigators indispensable to community surgeons will foster loyalty and increase patient volumes.

#### A True "Team" Effort

The multidisciplinary Navigation Team model is working well at MRCC. Our model is both cost effective and

comprehensive in scope. In other words, our multidisciplinary Navigation Team is more cost effective than hiring only one discipline such as RNs. Likewise, if the team consisted only of social workers or volunteers, there would be an absence of qualified expertise to work through the complex medical issues associated with cancer care. Instead, social workers are available to address issues such as assistance with transportation, linkages to community support groups, or assisting in completion of documentation for enrollment in alternative funding sources, freeing up the RNs and ARNP to deal with issues such as coordination of medical care and patient education. Augmenting the team with patient representatives to offer financial assistance has not only helped our cancer patients, it has also helped the cancer program by decreasing payer denials and improving patient access to funding alternatives.

While our patient navigation model is still evolving, early indications are

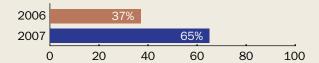
that the program is a success. Looking back at our outcome measures, we have improved patient satisfaction and increased patient volumes. In fact, since the inception of the first Navigation Team in 2006, the volume of cases across all locations has increased more than 30 percent. While it is difficult—if not impossible—to definitively correlate these volume increases to the work of the Navigation Team, when coupled with the improvement in

continued on page S14

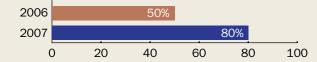
#### Figure 1. Percentage of Patients Giving a Score of 4 on MRCCs Cancer Patient Survey\*

Patients asked to use 1-4 point scoring on all questions with 1= Disagree; 2= Somewhat Disagree; 3= Somewhat Agree; and 4=Completely Agree.

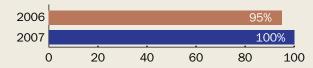
1. A member of our staff informed you of the details of your insurance coverage prior to the start of treatment.



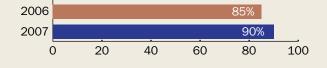
2. I was contacted by an oncology clinic staff member prior to my initial physician consult to answer any questions or concerns.



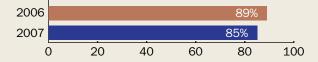
3. I was given written information regarding my medications and an opportunity to speak with the pharmacist.



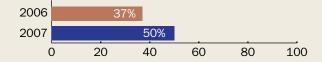
4. My questions about my treatment plan and the potential impact to my life were answered by the nurse.



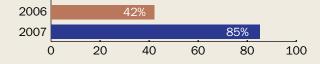
5. I was given assistance making appointments and getting appointments with other departments at MultiCare.



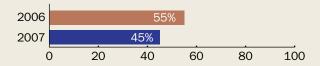
6. A dietitian was available to me to discuss nutrition and diet during my treatment.



7. I was provided information about access to community support services.



8. I had no transportation issues during my treatment.

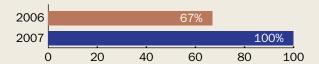


## **Practical Tips for Developing and Growing a Patient Navigation Team**

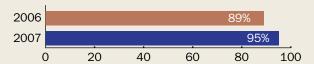
- Start small. Although your needs may be great, consider implementing a smaller navigation program with defined boundaries and objectives that can then be used as benchmarks for success and justification for program expansion. It's better to do a few program elements successfully and use that success to validate expansion than to allow the program to struggle with measurable outcomes due to "scope creep."
- Use a multidisciplinary model. Bringing together RNs, ARPNs, social workers, nutritionists, financial counselors, and other professionals can provide a depth of expertise in a cost-effective manner. Clearly define roles for each discipline on the team.
- Survey your cancer patients. Conduct a baseline survey
  of patient satisfaction administered prior to initiation of the
  navigation program so that success can be measured and
  reported to leadership.

- Listen to your cancer patients. Keep a log of patient success stories. These anecdotal accounts provide faces, emotions, and reality to patient navigation benefits that are not easily quantified. These human interest success stories help gain and sustain support for navigation programs and services.
- **Control program growth**. Evolving the program structure and scope in small intervals with demonstrated successes through each stage can garner confidence and support for continued expansion.
- **Expand the navigator role**. Asking patient navigators to liaise with your community referral base—patients and referring physicians—can help increase patient volumes and grow your navigation program.
- **Establish an advisory council**. An advisory council of providers, patients, and family members can help direct the goals and work of your Navigation Team.
- Set up a foundation to help fund the program. A foundation can accept community donations and other funds to pay for supplies, materials, and programs associated with the work of your navigation team.

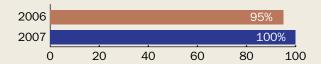
9. My pain was monitored and managed during my treatment.



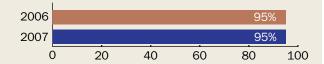
13. I understood potential side effects of my treatment and how to manage them.



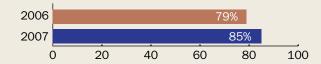
10. My family was well supported by the clinic staff.



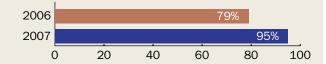
14. I understand when I need to call my physician.



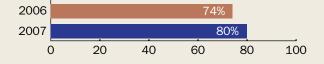
11. My quality of life was maintained through my treatment.



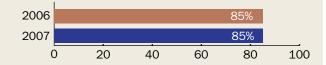
15. All of my questions were answered understandably.



12. I knew what to expect through each stage of my care.

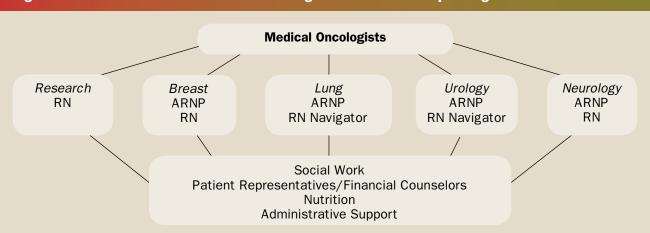


16. I know who to call when I have problems or questions.



<sup>\*</sup>The 2006 survey established a baseline before the initiation of the Navigation team.

Figure 2. Possible Future Directions for Targeted Disease Group Navigation Teams



patient satisfaction, it is reasonable to assume that there is some correlation between patient volumes and the Navigation Team.

For example, preliminary findings related to our lung cancer patients may support the positive benefits of disease-site-specific navigation. The ARNP has only been in the position for six months; however, in that time there has been a sudden and definite increase in lung cancer patients entering the program. Preliminary data for the past four months show a 20 percent rise in referrals for lung cancer, and the ARNP has had early success developing close relationships with the leading pulmonology and cardiothoracic practices in the area.

Today, our Navigation Team consists of six navigators (five RNs and one ARNP). Four of these navigators are disease-site-specific and two are generalists who provide care management support for those patients whose cancer does not fall into one of the four focused disease sites. The team also includes two social workers, a nutritionist, and three patient representatives. Our plan is to add an additional nutritionist and an additional patient representative in the next 12 months. Collectively this multidisciplinary team supports all cancer patients at five clinic locations.

#### **Lessons Learned**

We are still working to understand the appropriate workload for the Navigation Team and the right mix of disciplines. In addition, the Navigation Team's work continues to evolve; as one segment of identified needs is addressed, more needs are identified.

One critical decision made early in the process was to define boundaries

for the Navigation Team to work within. We communicated those boundaries to physicians and other staff in an effort to keep our Navigation Team focused. Without clearly defined boundaries, "responsibility creep" can easily pull the Navigation Team in so many directions that team members cannot be effective in their supportive roles and there will be no measurable success points that can then be used to help justify expansion of the team. Even today, with the expanded Navigation Team, the definition of boundaries is crucial to sustain focus and experience success.

Another important step taken in the program's early stages was conducting the baseline survey of patient satisfaction in key areas, and then focusing the Navigation Team on improving those specific indicators. As success benchmarks are achieved through patient satisfaction scores or increased patient volumes and the team is expanded, the boundaries can likewise be expanded.

Our model is still evolving and being refined. The structure of MRCC's Navigation Team is defined based on success and continued unmet need as the next iteration is taking shape. Figure 2 illustrates the direction that our program appears to be taking. In addition to meeting the support needs of patients and driving patient volumes, another important factor that comes into play is the increasing shortage of oncology physicians. With this new model, the diseasesite-specific ARNPs will continue to liaise with referring physicians, but they will also start to become responsible for routine follow-up care of patients, freeing the oncologist to focus his or her expertise on initial consultations and management of complex cases. In this

model the RNs, social workers, nutritionists, and patient representatives continue to play their supportive roles. This model is still a concept, but in looking at the unique contributions of the ARNP in our current thoracic model it seems there are advantages in patient care and care delivery economies in moving toward this next iteration.

Reflecting back over the evolution of the Navigation Team, several key actions contributed to the team's success, including:

- Starting small
- Using a multidisciplinary model
- Surveying patients and listening to what they had to say
- Controlling program growth
- Expanding the navigator role
- Establishing a patient advisory council and listening to their experiences and advice in setting priorities and identifying unmet support needs
- Establishing a foundation to help fund some of the resources of the program.

For more information, see "Practical Tips for Developing and Growing a Patient Navigation Team" on page S13.

As 2007 survey results show, MRCC's Patient Navigation Team has clearly benefited our patients and our cancer center. Today, we call the navigation program at MultiCare Regional Cancer a successful "work in progress." Our hope is that other community cancer centers can learn from our program as we continue to evolve to meet the needs of our patients, families, physicians, staff, and community.

David Nicewonger, MHA, is Administrator, Cancer Services Careline, MultiCare Health Systems in Tacoma, Wash.

## **Patient Navigation at Billings Clinic**

#### an NCI Community Cancer Centers Program (NCCCP) Pilot Site

by Karyl Blaseg, RN, MSN, OCN, BC

A cancer diagnosis often produces an overwhelming emotional response, including feelings of shock, denial, fear, anxiety, anger, grief, and/or depression. Because a multitude of medical tests and consultations typically are needed to determine a definitive diagnosis and course of treatment, a cancer patient's path through the healthcare system can be complicated and confusing. Even worse, some patients may not fully comprehend the importance of prompt evaluation and treatment of their disease. To address these challenges, more and more cancer programs are looking to assist patients through this process. Here's how Billings Clinic embarked on its journey to create a care navigation program to meet the unique needs of the people it serves.

hen medical oncologist Thomas
Purcell, MD, joined Billings Clinic in

Purcell, MD, joined Billings Clinic in 2003, his vision was to create a regional comprehensive cancer center designed to be a premier destination facility characterized by an interdisciplinary team approach to cancer treatment. Based on his previous experience with patient navigation at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, patient navigation was central to this vision. Dr. Purcell had witnessed

the many successes and contributions navigation brought to comprehensive cancer care and was successful in championing the initiation of a patient navigation program at Billings Clinic by engaging senior leadership's support and relating program benefits to potential effects on existing market share.

#### **Our Navigation Model**

Billings Clinic launched its patient navigation program in 2003 with one navigator. The model put patients at the center of decision making; with patient navigation to assist them as they move through the cancer treatment continuum (see Figure 1). Over the last six years, the navigation program has grown in an organized, phased manner into today's team of eight navigators (see Figure 2). This phased approach allowed Billings Clinic to build upon incremental successes, expanding the scope of the program with a focus on navigating a majority of patients served in our vast geographic service area (see "Serving, the Underserved in the Last Frontier, page S22). The overall goal of our navigation program is to ensure seamless and coordinated care among the physicians, the diagnostic tests, and the cancer treatments, while offering education, support, and guidance to help patients and families cope with their challenges.

All of our patient navigators are registered nurses with oncology experience. The navigator's primary focus: to provide one-on-one support and coordination of services for cancer patients and their families as they move through the care pathway. Specifically, Billings Clinic patient navigators:

- Assess for clinical, emotional, spiritual, psychosocial, financial, and other patient needs
- Coordinate the timely scheduling of tests, procedures, appointments, and treatments
- Help eliminate barriers to obtaining a definitive diagnosis
- Ensure patients receive a treatment plan that is understandable and feasible
- Reinforce patient education and direct patients and families to available resources and supportive services
- Facilitate access to clinical trials.

#### **Phase I—2003**

As stated above, our program started with a 1.0 FTE patient navigator who received referrals for patients requiring complex coordination of care after diagnosis and upon treatment initiation. At the outset, the navigation



The Billings Clinic disease-site-specific patient navigation program employs eight RN navigators.

We found that the mere presence of a patient navigator on a consistent basis within these departments enhanced communication, trust, and provider referrals for navigation services.

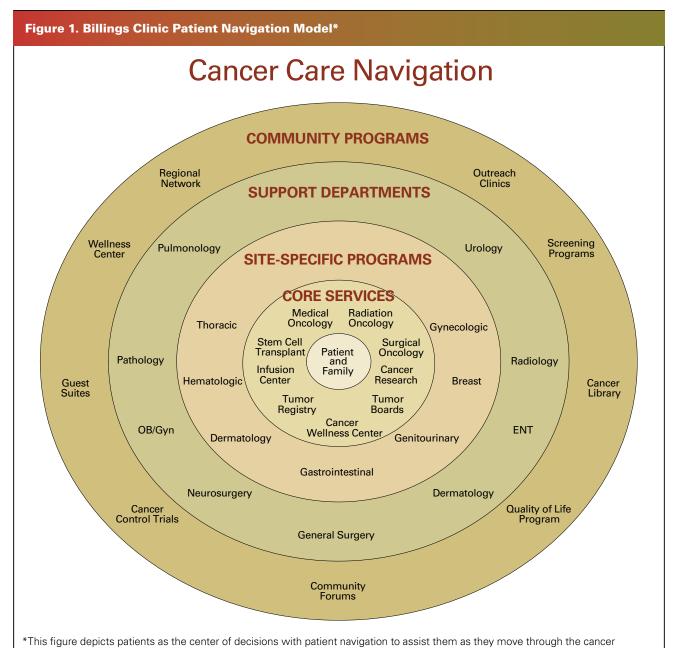
program focused on two primary areas. The first goal: to establish an understanding of navigation within the Cancer Center among the medical oncologists, staff, and support services. The second goal: to develop

standardized educational and support materials for patients.

#### Phase II—2004

Phase II of the program brought a second 1.0 FTE patient navigation posi-

tion to the team, as well as a clearer focus on site-specific navigation. We assigned each navigator two of the most common cancer types—breast and colorectal cancers and lung and prostate cancers. At this point, it



treatment continuum rather than responsibility for coordination and communication between multiple disciplines and specialists being left to the patient alone. ©Billings Clinic

#### **Current Scope of Navigation Services**

Some of the most common roles and responsibilities of patient navigators at Billings Clinic include:

- Acting as the single point of contact for patients and families, including telephone triage regarding symptom management
- Accompanying patients to initial appointments during diagnosis and treatment planning period
- Assessing patients' physical, emotional, psychosocial, spiritual, and financial needs
- Initiating referrals (both internal as

- well as connecting patients with community resources)
- Coordinating diagnostics, procedures, and specialist appointments
- Providing patient education
- Collaborating with physicians and following up on multidisciplinary tumor conference recommendations
- Contributing to multidisciplinary program development, such as education materials, clinical pathways, and quality studies.

Current

**Navigation** 

became important for navigators to collaborate with other departments within Billings Clinic, including Gastroenterology, Pathology, Primary Care, Pulmonology, Radiology, Surgery, and Urology. This ongoing collaboration allowed us to:

- Promote a better understanding of patient navigation
- Simplify referral and care processes
- Identify system impediments to timely and optimal cancer care.

We found that the mere presence of a patient navigator on a consistent basis within these departments enhanced communication, trust, and provider referrals for navigation services.

## Assignments

- Breast (cancer)
- Breast (diagnostic)
- Gastrointestinal
- Genitourinary, Head and Neck, Sarcoma, Skin
- Gynecologic
- Hematological
- Lung, Neurological, Unknown Primary
- Regional

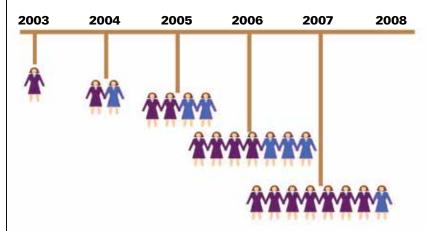
#### Referrals

All navigated patients receive automatic referrals to the dietitian, social worker, financial counselor, and multidisciplinary tumor conference. As appropriate, patients navigated will be referred to:

- Medication assistance programs
- Subsidized programs
- Support groups
- Integrative medicine
- Genetic counseling
- Cancer research
- Home health and/or hospice
- Lymphedema program.

## Figure 2: Evolution of patient navigation positions using a phased approach

## A Historical Perspective



### Phase III—2005

Two additional 1.0 FTE patient navigator positions were added during phase III. Each of the patient navigators assumed primary responsibility for one major cancer site (breast, colorectal, lung, and prostate), with hematological cancers distributed among three of the navigators due to the intense needs of these patients. Major goals during phase III included:

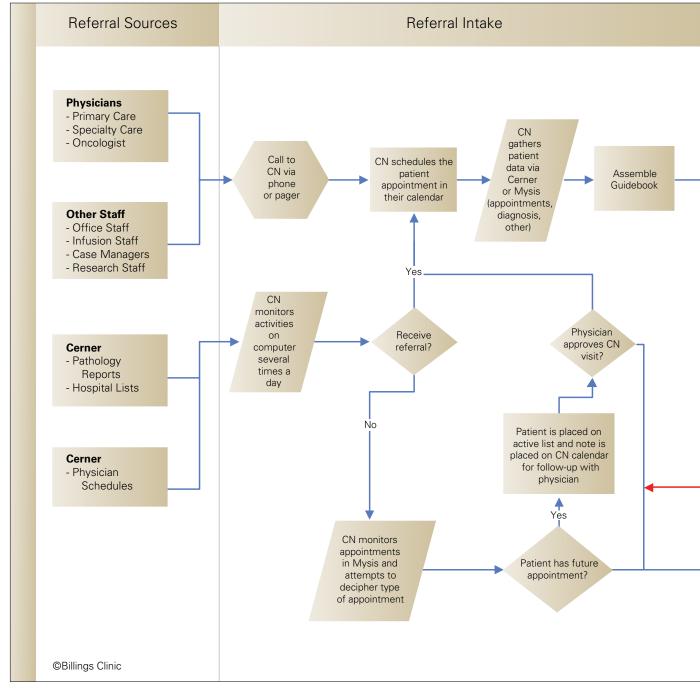
- An increased focus on processes to clarify role expectations
- The development of a variety of flowcharts and fishbone diagrams (see Figures 3 and 4)
- A navigator orientation manual to ensure consistency among the patient navigators.

Marketing and public relations promotions continued to increase community awareness of the program. In addition, we designed and carried out a patient satisfaction survey to obtain feedback on the effectiveness of our navigation program (see Figure 5).

#### Phase IV—2006

Phase IV of our patient navigation program involved the largest expansion yet—three additional 1.0 FTE patient navigator positions. One navigator was assigned to hematological malignan-





cies, another to gynecologic cancers, and the third focused on breast diagnostic navigation. Our program was now seven navigators strong, with one navigator assigned to the organization's Breast Center rather than the Cancer Center. The breast diagnostic navigator guides patients from abnormal mammogram through diagnosis:

- Ensuring timely scheduling of diagnostic procedures
- Providing appropriate patient educa-

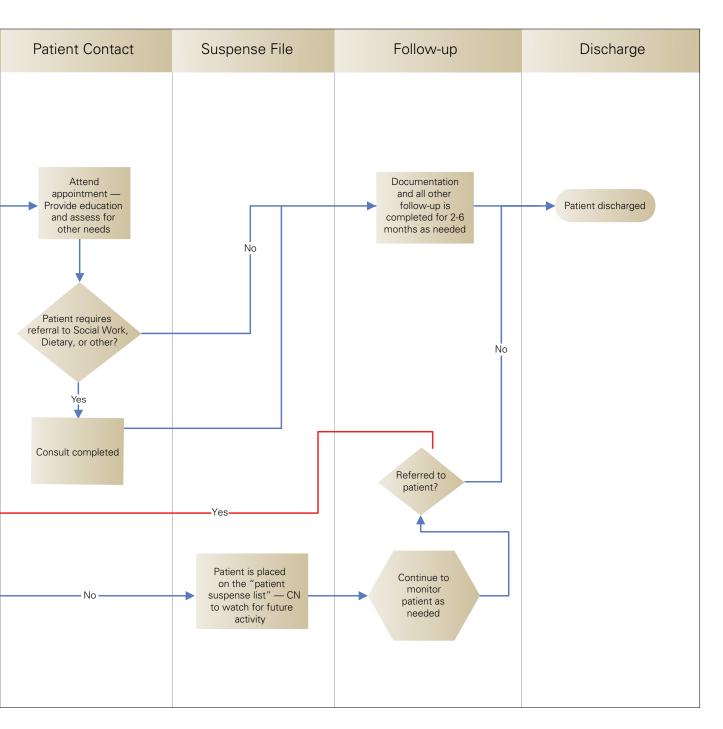
tion and support during proceduresNotifying patients promptly of diagnostic results.

Patients with a cancer diagnosis are then transferred to the breast cancer navigator who further coordinates services related to treatment and survivorship.

Major program efforts during phase IV included the development and advancement of multidisciplinary teams

led by physician leaders in collaboration with the site-specific navigators for breast, gastrointestinal, genitourinary, gynecologic, hematological, and lung cancers.

Expanding to seven navigators allowed us to focus on establishing meaningful program metrics. In addition, our physicians expressed a strong desire to have a designated navigator for all patients undergoing multimodality treatment. With this request, work



began on establishing a patient acuity system whereby navigation assignments could be determined based on estimated workload rather than mere navigator-to-patient ratios. One lesson learned throughout the previous three phases of program implementation was that patients' needs varied widely based on tumor site, stage at diagnosis, treatment(s) chosen, and existing support systems. Because of these variables, we felt that distributing the varia

ous tumor sites based on volume alone was unrealistic. Instead, we completed a workload analysis and defined seven different acuity levels (see Figure 6).

Next, we evaluated the previous year's cancer registry data, including number of cancer cases by type and stage. In consultation with the patient navigators, we matched defined acuity levels with the various stages of disease by tumor site. Then an acuity calculation was created (volume multiplied

by acuity level = estimated workload). While the acuity system was not scientifically validated, it served as an effective mechanism to distribute the various tumor sites so that all patients undergoing multimodality treatment could be assigned a patient navigator.

#### **Phase V—2007**

In 2007 Billings Clinic was one of ten organizations across the United States chosen to participate in the

Figure 4: Multidiscplinary Cancer Patient Care Social Worker Placement (LTC, Assisted Living, Temporary Intake Assessment Financial Counselor Housing) Other (Financial Screening, Social Support. Emotional State. Support Groups Community Resources) (General, IP, Financial Hope for Assessment Payment Tomorrow) Schedule Counseling & Follow-up Financial Evaluation Counseling (Refer as needed) Single Patient Contact for Therapeutic Ca Patient Entire Tx Course Counseling Education Ca Patient Treatment Telephone Education Delivery Triage (Symptom Management. Complex Care) Coordinate Specialist Appointments Communication/ Licensed Counselor **Treatment Nurses** Outreach Resource Refer Patient to Tumor Board Multidisciplinary Program Development Follow-up on (Pathways, Education, Tumor Board Quality Studies) Recommendations Care Navigator

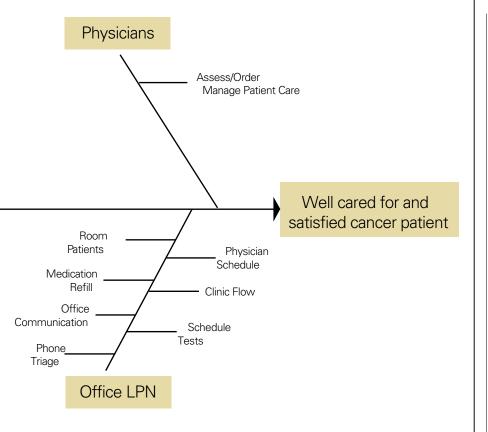
National Cancer Institute's (NCI's) Community Cancer Centers Program (NCCCP) three-year pilot project. As part of this pilot, Billings Clinic Cancer Center added a regional navigator to assess the rural and frontier regions served through the extensive oncology outreach program. This navigator advocates for the individuals in those regions and identifies the needs of those cancer patients. A significant

**©Billings Clinic** 

portion of the regional navigator's time involves traveling and relationship-building through face-to-face interactions with community physicians, agencies, and organizations. As a result of this networking, the regional navigator has hosted two navigator training programs for individuals who recently assumed patient navigator roles within their own organizations in the region. The regional navigator

also helps connect patients with local resources and collaborates with community-health offices and tribal leaders to promote community education and increase prevention awareness and early-detection screening programs (e.g., mammograms, Pap smears, fecal immunohistochemical testing, and prostate specific antigen screening) in the rural and frontier regions. To date, seven Cancer 101 programs have





- Developing an electronic version of the patient navigation intake worksheet
- Refining existing electronic documentation templates
- Successfully launching a multidisciplinary lung clinic coordinated by the lung patient navigator in collaboration with pulmonologists, thoracic surgeons, medical oncologists, and radiation oncologists
- Planning for two additional multidisciplinary clinics (rectal and prostate).

The success of the program has led other clinical departments to request information regarding the development of patient navigation programs for other chronic diseases.

...we began to
evaluate additional
data related to
timeliness of care...
and appropriateness
of care...

been offered to Native American communities in Montana and Wyoming.

During this phase, patient navigators looked again at program quality metrics. Previously metrics had focused largely on patient satisfaction and program volume, including the number of new patients navigated by cancer type and referrals initiated. Now, we began to evaluate additional data related to timeliness of care (time from abnormal

finding to diagnosis and time from diagnosis to treatment initiation) and appropriateness of care (compliance with clinical pathways).

#### Phase VI—2008

For the first time since we initiated the patient navigation program, no additional positions were added during 2008. However, program enhancements throughout the year included:

#### **Future Directions**

Upcoming endeavors for patient navigation at Billings Clinic include the implementation of two additional multidisciplinary clinics (rectal and prostate), which will be coordinated by the site-specific navigators in collaboration with involved physician specialties. In addition, each multidisciplinary program will establish ongoing quality measures that span the continuum of care for breast, colorectal, lung, prostate,

continued on page S24

#### Serving the Underserved in the Last Frontier

Significant healthcare disparities exist in the region served by Billings Clinic Cancer Center, a vast geographic area of 207,000 square miles encompassing the state of Montana, the northern half of Wyoming, and the western edge of North Dakota. This service area is 33 percent larger than the entire state of California, with a population of approximately 1.25 million people (compared to over 33 million in California). A lack of access to primary care physicians is a well-known characteristic of the region with approximately 87 percent of Montana counties (some as large as entire states) designated as Health Professional Shortage Areas, Medically Underserved Areas, and/or Physician Scarcity Areas.

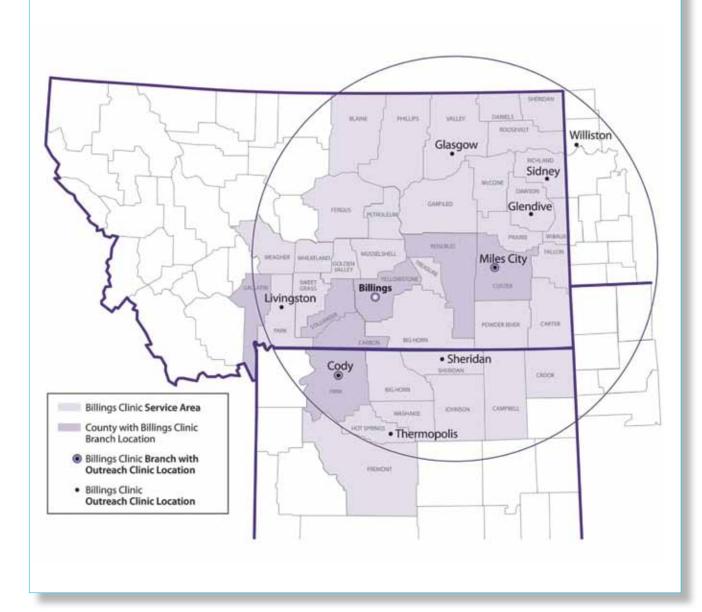
Cancer rates are driven by a complex set of social, economic, cultural, and health system factors. The lack of local medical care, including cancer prevention information and screening, affects the stage at the time of cancer

diagnosis—an important predictor of the outcome of treatment. Between 2002 and 2006, less than half of all cancers (48 percent) in Montana were diagnosed at the local stage. Twenty percent of all cancers diagnosed were regional and 22 percent were diagnosed at a distant, or metastasized, stage.<sup>1</sup>

Regionally, Billings Clinic has long been dedicated to working collaboratively with communities to address healthcare disparities in remote and frontier areas. Each month, the Billings Clinic Cancer Center provides 21 outreach clinics in 9 rural communities (see map below).

#### **References**

<sup>1</sup>Montana Central Tumor Registry. (2008). Cancer in Montana 2002-2006: Montana Central Tumor Registry Annual Report. (Montana Department of Public Health and Human Services). Helena, MT.



#### Figure 5: Billings Clinic Cancer Center Care Navigation Survey



Patient Name:			Navigator Na	me:				
Gender:	O Male	O Female	Cancer Type:	O Bladder O Breast		O Myelo O Ovaria		
Age:	O < 35			O Cervical		Peritor		al y
Age.	O 35-44			O CNS		O Pancre		
	O 45-54			O Colon &	Rectum	O Prosta		
	O 55-64			O Esophag		O Renal		
	O 65-74			O Head & I	Neck	O Sarcor		
	O > 75			O Leukemi		O Testic		
				O Lymphor		O Uterin		
				O Lung & E O Melanon		O Other:		
				O IVIEIDITION	ia/SKII I			
of the service qua Patient had quality I was allowed	section bel lity offered uick, seaml I an approp	ow, Care Naviga during this treat less <b>access</b> to d priate <b>level of in</b>	•			Yes O O	No O O O	N/A O O O
	section belotelephone	follow-up.  Billings Clinic. Is _	available? I am calling	ı on behalf d				
I would like you to	respond to	each statement v	the care you received. Is this a g with a number indicating your ag eas a high number indicates your	reement. A	low numi	ber would	indica	te you
My cancer care w	ras provider	d in a <b>timely fa</b>	shion		_	5 6 7 8		
•	•	_	y unique treatment plan.			0000		
	was <b>impo</b>	•	ng seamless care between diff			0000		
		t <b>ed</b> my care to r	meet my unique needs.	1	0000	0000	000	)
My care navigator understand.	answered	I my questions	in a manner I could easily	,	0000	0000	000	)
Was there any navigator to give		information or	education that would have I	peen bene	ficial for	your care	Э	
Do you have ar	ny comme	nts you would	like to make?					
Thank you for taki the best possible			these questions. Your input is	very impoi	rtant so th	nat we ca	n offe	r
Date/Time of All Atter	npts	Staff Signature						
1					-			
2								
3						@Bill	ings Cli	nic

## [Patient navigation] has become the link that integrates every aspect of patient care...

Figure 6: Patient Nav	igation Acuity Scale	Billings Clinic
Acuity Scale		Description
0		No navigation
0.5	Initial guida	Meet patient if referral received; ance/education/coordination as needed; Typically no follow-up required
1		Meet patients upon diagnosis; Initial guidance/education/coordination; Typically no follow-up required
1.5		Meet patient upon diagnosis; Coordination of multi-modality treatment; ping guidance/education for 3-4 months;
2		Meet patients upon diagnosis; Coordination of multi-modality treatment; Moderate intensity of needs; dance/education for 5-6 months or more
2.5	High intensity of needs, often inpation	Meet patients upon diagnosis; Coordination of multi-modality treatment; ent hospitalizations associated with care ance/education for 6-12 months or more
4 ©Billings Clinic	High intensity of needs, often associated v	Meets patient upon diagnosis; Coordination of multi-modality treatment; with care coordination outside of facility; ance/education for 6-12 months or more

hematological, and gynecologic cancers. The navigators will monitor and report on the measures quarterly by using a clinical quality dashboard. Lastly, given the success of patient navigation within the Cancer Center at Billings Clinic and the recent interest expressed by other service lines, it would not be

surprising if patient navigation programs for other chronic diseases emerged over the next year.

In summary, patient navigation is integral to the interdisciplinary team approach to cancer treatment that Billings Clinic proudly endorses. It has become the link that integrates every

aspect of patient care through the facilitation of timely communication, seamless patient flow, and optimal clinical outcomes.

Karyl Blaseg, RN, MSN, OCN, BC, is manager of cancer programs at the Billings Clinic in Billings, Montana.

## **Growing Your Patient Navigation Program**

A step-by-step guide for community cancer centers

by Joann Zeller, MBA, RTT, CTR

Good Samaritan Hospital is a 232-bed community hospital serving a 15-county area in both Indiana and Illinois. We opened our new Cancer Pavilion in April 2008.

state-of-the-art facility designed to bring all of our cancer patient services under one roof, the completion of the Cancer Pavilion fulfilled the "bricks and mortar" portion of our strategic plan. Next we focused on expanding our existing patient support services. These included social services, dietary counseling, patient support groups, financial counseling, rehabilitation, pastoral care, and two certified RN breast health navigators. Our plan to increase patient support services included growth on several fronts:

- Hiring a patient support specialist to assist with insurance authorizations. This staff member will also help patients apply to drug replacement programs as well as organizations that assist with co-pays.
- Adding a dedicated social worker in the outpatient setting to help grow our offering of support groups and build a survivorship program.
- Expanding the use of patient navigators across the service line.

If you are a community hospital similar in size to our facility, you may face the same challenges that we do. You have a dedicated, well-educated staff, as well as varied support services, but you lack a formal program to ensure that all patients are getting the information and support that they deserve.

Patient navigation has been a growing force in cancer care since the ground-breaking work by Harold P. Freeman, MD. Patient navigators can serve as compassionate, effective "guides" to help patients move through the complexities of the healthcare system. While that is exactly what we wanted for our patients, we did not have the luxury of a hospital-funded FTE to devote to the project. Our first thought was to write a grant, but our experience has shown us that you have better success being funded when you have a well-defined program prior to submitting a grant. Our solu-

tion was to implement a scaled-down patient navigation program within our existing structure. This smaller program would be just the first step toward establishing a fully developed, comprehensive Patient Navigator Program in our facility. Below is a description of the eight-step process we devised as a road map to navigate toward success.

### Step 1: Analyze the Role of the Patient Navigator

Analyzing the patient navigator role allowed us to identify key functions we could realistically take on with our existing staff. Our goal: to successfully incorporate as much of the navigator role into our program as possible, while documenting its effectiveness. We believed these actions would best prepare us for submitting grant applications in the future. And procuring grant funds for a full-time patient navigator would serve to fully expand the role and be a bridge to eventually having a hospital-funded FTE navigator position.

Patient navigator key time points are:1

- Connecting individuals to screening
- Following patients post-screening
- Assisting patients through treatment
- Providing support to survivors.



Traci Hill, RN, (left) is one of two certified breast health navigators at Good Samaritan Hospital's Breast Care Center.

Even in a limited capacity, if applied to specific key time points, our patient navigators could achieve the most basic functions which are:

- To eliminate barriers to care
- To ensure timely delivery of services
- To save lives from cancer
- To improve patient satisfaction.

## Step 2: Identify Our Existing Strengths

Our program already had in place a number of components that would support a navigation program including an established breast health navigator, a physician champion, certified staff, existing support services, and accreditations.

Established breast health navigators. Our Breast Care Center has a well-established patient navigation program, a huge advantage to our facility. Approximately 80 analytic breast cancer cases are accessioned by our registry each year. In 2006 Good Samaritan Hospital established the Breast Care Center to provide comprehensive care to those patients who present with a positive diagnosis as a result of screening. As part of this program, Traci Hill, RN, received training

to become a Certified Breast Health Navigator (CBHN). She completed a 40-hour comprehensive training program on all aspects of patient navigation for breast cancer patients through EduCare, Inc., and received certification. A second nurse, Cindy Mouzin, RN, was also sent for breast health navigator training and certification. She now assists on all biopsies in the mammography portion of the Breast Care Center. Together these two nurses provide complete navigation services for all of our breast cancer patients.

**Physician champion.** We have a strong physician champion for patient navigation at our facility. Even better, we did not have to look for a champion—he came to us. Kurt Maddock, MD, is a breast surgeon and medical director of our Cancer Program. He championed the CBHN training for the nurses in the Breast Care Center. As a strong advocate for patient navigation, we have his full support as we expand patient navigation across the cancer service line.

Certified staff. The majority of our nurses are ONS certified. As stated above, our Breast Health Navigators are also certified. Our nurses have completed the Certified Breast Care Nurse (CBCN) courses offered by the Oncology Nursing Society (ONS) and will be sitting for the exam in the spring. To date, we have not pursued any general patient navigation certifications.

**Existing support services.** Our cancer center already provides the following supportive care services to our cancer patients: social services, dietary counseling, patient support groups, financial counseling, rehabilitation, and pastoral care.

Facility accreditations. Our cancer program has received several accreditations including: JCAHO; ACoS, American College of Surgeons CHCP; Magnet status (this speaks to the dedication of our nurses and our hospital's support of the continuum of care for the patient); and designation as a Breast Imaging Center of Excellence

(BICOE) through the American College of Radiology (ACR).

### Step 3: Identify Our Challenges as a Community Hospital

Our cancer center faced several challenges to implementing patient navigation. For example, our screening programs take place across the community and are not centralized through our hospital.

Another challenge: all of the patient services listed under our strengths are shared services within the hospital. In other words, they are not immediately available to outpatients without scheduling an appointment.

We also faced staffing issues. Specifically, our current RN FTEs have limited hours to fill the role of Patient Navigator.

We saw a lack of an official survivorship program as another barrier. (Developing a survivorship program is a cancer program goal for 2009.)

## Step 4: Develop the Bones of Our Navigation Program

Now it was time to develop policies and procedures to formalize our navigation process. We started by looking at the number of patients who were going to use our navigation services each year.

Our literature search revealed an effective navigation ratio of 1 FTE for 25 to 30 patients under treatment and 75 to 80 post-treatment. Our cancer center treats approximately 50 patients a day and has 450 analytic cases per year. We have 7 oncology nurses and 2 certified breast health navigators. Of our analytic cases per year, 80 are breast cancer patients. The remaining cases divide into approximately 50 cases per nurse. These cases are a combination of patients undergoing treatment and those in follow-up. The simple rule of thumb at our facility is the first nurse to communicate with the patient becomes that patient's navigator. This approach works for us because all of our nurses are scheduled in the same work areas with the same rotating duties. No one is specifically assigned to education or to patients experiencing chemotherapy or radiation therapy for the first time.

Prior to initiating the navigator role (beyond the breast care center) we met several times with our nurses to discuss what the change would mean to our patients, how best to manage the process, and what documents they thought would be worthwhile. We wanted to give patients an easy way to organize their papers and keep track of smaller forms as they moved through the healthcare system. Everyone agreed to use an expandable file folder with a fold-over top to hold the forms. The folder had a place for the patient navigator's card, as well as a card for the managing physician. We also included an insert for other business cards that patients invariably receive during office visits. After selecting a file folder with 12 expandable pockets, we organized the educational information under five headings:

- 1. Intake Forms. This section includes forms for the initial entry into the program: Intake Form, Identification of Barriers to Care, and a Weekly Contact Record. Our tools were based on templates provided through EduCare, Inc., and the Pfizer patient navigation toolkit, which is available online at www.patientnavigation. com. Using the information from the intake form, navigators can make appointments for patients based on their self-identified needs. These can include dietary, rehabilitation, nutrition, financial, and assistance from our Patient Support Specialist.
- Medication Record. This record is fully reconciled with the patient's hospital medication record.
- 3. Patient Support Services. We include flyers for our American Cancer Society (ACS) support groups, as well as information on our Resource Library and Boutique, which offers free wigs, hats, and mastectomy bras.
- **4. Insurance**. This information is generated at patient registration, but we

Good Samaritan Hospital's new Cancer Pavilion opened in April 2008.



found that having a copy in the folder has been helpful to patients as they make their various office visits.

- 5. Demographics. This information is also generated at patient registration. And again, patients have found it helpful to have a copy in their folder as they make their office visits. Our demographic form contains basic information such as address, next of kin, insurance information, etc.
- 6. Education. We do not pre-load this portion of the file folder. Instead, the information is specific to the patient and his or her disease process. The navigators believe it is important to first review the information with the patient prior to putting it into the file folder.

Our hope is that patients view the file folder and all of its documents as their own "tool box."

### Step 5: Initiate the Navigator Role

Once the formal processes and tools were in place, it was time to educate the community about our new navigation program. Our patient navigation service is featured on hospital and cancer center brochures, on the hospital's website, and on flyers available in the cancer center's resource area. The most effective communication, however, is from our navigators themselves when they first see the patient. When we have fully expanded our program and incorporated navigation services at the most basic screening level, we anticipate a full marketing campaign to include our regional physicians.

## Step 6: Measure Program Effectiveness

Our Cancer Program has an ongoing process improvement initiative that tracks our current compliance rate with

the American College of Surgeons CP³R NCDB studies. Beginning in 2009, ACoS requires accredited facilities to not only report compliance rates to their own Cancer Committee but also to set benchmarks and establish plans to address low performance rates. Our facility went one step further and is now reporting current data four to six months out. We felt this was important because the online NCDB data reflect 2006 data with 2007 soon to follow.

The navigators are all well-versed on the CP³R studies and the qualifications for the patient subsets. We felt this was an ideal way to use and measure the patient navigator skill set. If navigators know up front that the patients' disease and stage qualifies them to be included in a study, they can be proactive in watching for the appropriate appointments for specialty consultations. More importantly, the navigators can make sure that the patient follows through on these appointments.

The resulting data on performance rates are tracked by our quality department and reported to the Cancer Committee six times a year.

#### **Step 7: Apply for Grant Funding**

The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (The Patient Navigator Act) was signed into law on June 29, 2005. This Act authorized \$2 million in FY 2006, \$5 million for FY 2007, \$7 million for FY 2008, \$6.5 million for FY 2009, and \$3.5 million for FY 2010 to the Health Resources and Services Administration (HRSA) to provide grants to eligible entities. The grants are to recruit, assign, train, and employ patient navigators who have direct knowledge of the communities they serve to facilitate the care and improve healthcare outcomes for individuals with cancer or chronic disease. This

legislation has increased both awareness of patient navigation and the number of available grants. Your local libraries may be an additional resource if they have user passwords to specific grant writing websites such as www. foundationcenter.org.

### Step 8: Transition to Hospital-funded FTE Employee

Our goal is to have a hospital-funded FTE patient navigator by 2012. Once our current, abbreviated navigated program has been in place for one year, we will submit grant applications. A grant-funded FTE will allow us to expand the navigation services to capture all patients receiving initial suspicious findings of what may be cancer. Establishing these expanded services will take some time as it will require structuring a system to gather community-wide screenings. If we are lucky enough to receive a grant to establish a comprehensive navigation program over a two-year period, we anticipate having well-established cost and effectiveness outcomes on the patient navigation program ready to submit for FTE approval in our hospital budget.

For our community cancer center, incorporating the patient navigator role, even in a limited fashion, has been well received and extremely valuable to our patients. Like many projects that seem overwhelming at first glance, growing a patient navigation program is achievable if you break it down into manageable sections. As Theodore Roosevelt said, "Do what you can, with what you have, where you are."

Joann Zeller, MBA, RTT, CTR, is director of Oncology Services at Good Samaritan Hospital in Vincennes, Ind.

#### References

<sup>1</sup> Katz Mira L. Patient Navigation Measurement Tools. *Overcoming Disparities through Patient Navigation. Detroit, Michigan. September 20, 2007.* 

### **A Regional Navigators' Network**

A First-person perspective

by Debbie Williams, RN

I am a breast health specialist and breast cancer patient navigator at Alexian Brothers Health System. I am also a breast cancer survivor. One important aspect of my role as a breast health specialist and breast cancer patient navigator is to be available for all and not limit the possibilities. I am fortunate and proud to work at a community cancer center that has valued the navigator role for more than nine years and has a well-established navigator program.

ne of my favorite quotes and one that I use today when I talk with my own breast cancer patients is—*To know the road ahead, ask those coming back.* These words sum up perfectly the value of our regional Network of Navigators in the Chicago area. Our Network has been meeting for a year now, and we often find it difficult to end our meetings on time because of the networking opportunities available. We have forged a bond between us based

on the new trails we are blazing!

Many patient navigators at facilities in our region are still working to break down barriers and establish their programs. They face many challenges including gaining approval and acceptance from their colleagues and caregivers. At the outset of navigation services, physicians may be uncertain of the navigator's role in patient care and may feel threatened. When working with new physicians who are unfamiliar with my patient navigator role, I explain that I serve as an extension of their office and can work alongside them to provide patients with the resources and information they need in order to feel in control and supported throughout their cancer journey. It can take years to earn the trust and support needed to be able to reach and help those who would benefit the most. Sometimes even the patients themselves are cautious about letting us slip into their lives at a time when they feel the most vulnerable and lost. However, patients soon recognize the navigator's value and that our office is a safe and secure place.

In the same way that a new patient learns to navigate the healthcare system when diagnosed, we navigators are learning where and how to help patients in need so that our services will have the greatest impact. Our Network of Navigators is unique because our group is open to all navigators—those who are hoping to start a program as well as experienced navigators in an established program. Among our group are nurse navigators—the largest segment—and community-based navigators who provide education on detection and prevention and how to access the healthcare system for screenings and care. The need for navigation in

our region is great, especially with our underserved populations.

Our community has excellent resources available for patients, and our regional navigators' network is an opportunity for us to share information about these local resources. We also help support each other and network about ways in which we've succeeded in overcoming barriers to patient navigation. Our regional navigators' network is also a support group, providing an opportunity to share how difficult it can be to cope with the loss of a patient.

We meet quarterly, with each meeting held at a different facility in the region. We tour each others centers and work places and see firsthand what others have been able to accomplish. Our meetings start with an educational presentation, followed by networking and information sharing. We discuss the community we serve and the challenges we face. I encourage all communities to try and establish such a group. The networking possibilities and partnership opportunities are invaluable.

Debbie Williams, RN, is breast health specialist and breast cancer patient navigator at Alexian Brothers Health System in Elk Grove Village, III.

### **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

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



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

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

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. 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, III.

#### References

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. Last accessed March 10, 2009. 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.

## **Broward Health's Breast Cancer Navigation Program**

Meeting the needs of underserved patients

by Pia Delvaille, ARNP, MSN

Broward Health, a nonprofit community health system, is one of the ten largest public health systems in the United States. Broward Health has more than 30 healthcare facilities including Broward General Medical Center, North Broward Medical Center, Imperial Point Medical Center, Coral Springs Medical Center, Broward Health Weston, and Chris Evert Children's Hospital at Broward General. Broward Health is a medical safety net for Broward County residents. For more information, go to www.browardhealth.org.

roward Health is a community healthcare system serving 1.7 million residents in the northern part of Broward County in southeastern Florida. Our healthcare system is responsible for the care and treatment of uninsured patients in this geographic area. According to 2007 data from the U.S. Census Bureau, approximately 340,000 residents within Broward County fall into this patient population. The Breast Cancer Navigation Program at Broward Health began in September 2006 when we realized that our healthcare system was becoming more and more difficult for patients to navigate. Multiple obstacles hampered our patients from diagnosis through treatment—ranging from uninsured patients without funds to pay for care to patients without transportation to come in to receive care. Accordingly, our Breast Cancer Navigation program was designed to serve this underserved population.

#### **Reaching Out to the Underserved**

We educate our community on the screening guidelines for good breast health through outreach programs conducted by our physicians, nurses, and outreach staff. Broward Health also offers several options for free mammograms and clinical breast exams through our healthcare system and affiliated community resources.

In 2008 Broward Health provided 29,380 mammograms, nearly 3,000 to women who were uninsured and could not afford to pay.<sup>1</sup>

In 2006 Broward Health applied for a patient navigation grant through the American Cancer Society (ACS). We received a grant of nearly \$150,000 from the Florida Division of the American Cancer Society. allowing us to establish our Breast Navigation Program and to hire one full-time RN patient navigator.1 This effort was spearheaded by Nicholas Tranakas, MD; Lori Kessler, manager, disease state, and the author. The grant was specifically used to fund the RN patient navigator position. The RN navigator is located in the Case Management Department, and she travels to the different Breast/Cancer Centers throughout the Broward Health System. Initially, the navigator was selftaught, using the Navigator Pathways and the Patient Navigator Training Manual from the HANYS Breast Cancer Demonstration Project and Pfizer Oncology. She later attended the Harold P. Freeman Patient Navigation Institute certification course in Harlem, N.Y.

Our Breast Cancer Patient Navigation program was designed to navigate medically underserved women of all ages, living below 200 percent of the Federal Poverty Level, who received an abnormal mammogram.<sup>2</sup>

#### **Our Team At-a-Glance**

Our first step was to establish a navigation planning team composed of Nicholas Tranakas, MD; Pia Delvaille, ARNP, MSN; and Paulet Reyes, RN, BSN. The team was responsible for establishing criteria and guidelines for referral to the Breast Navigation Program. The next step was to introduce the navigation program to all Broward Health departments, clinics, and community affiliates who would be involved in referral and care of the patient. To accomplish this, the planning team scheduled appointments to meet with these groups during their staff meetings.

Next, the navigation planning team developed forms for patient referrals, patient intake, program evaluation, patient progress notes, and a referral log (see pages S34–S38).

With tremendous growth in the first year, our navigation program soon outgrew the capabilities of our single nurse navigator. In 2007 we received a \$150,000 AVON Foundation grant, which allowed us to expand our navigation services by adding a bilingual social worker who is also a trained mental health professional.<sup>2</sup>

Today our breast cancer navigators are a part of the Comprehensive Cancer Center and Breast Center Team. The navigators' offices are located in the Disease State Management Department, and they report to the Manager of Disease State Management and the Breast/Cancer Center ARNP.

An abnormal finding on a mammogram triggers a patient referral to the breast cancer navigator who does a detailed intake to assess the patient's needs. The patient is then in the navigation program through completion of care. If the patient's work up is negative for cancer, the patient is put back on the schedule for follow-up as recommended by the physician, and the patient is educated and told to call for any changes or concerns. Once patients are diagnosed with cancer,

#### Services Offered by the Breast Navigation Program

- Assessment of patients and identification of barriers or possible barriers to care.
- Assistance with paperwork needed to access healthcare system for care.
- Help scheduling appointments in a timely manner.
- Identification and help accessing national and community resources.
- Weekly communication with patients while they are undergoing treatment.
- Ongoing communication with the multidisciplinary team to ensure seamless care of the patient.
- Assistance to establish a medical home (i.e., a facility where patients can receive healthcare).
- Continued support of patient on a quarterly basis once treatment is completed.

#### **Table 1: ACS Benchmarks/Broward Health Outcomes**

	ACS	Broward Health
American Cancer Society estimated benchmark for navigation from abnormal mammogram to care	53 days	51 days
Time from abnormal findings to diagnosis	13 days	13 days
Time from positive diagnosis to initiation of treatment	37 days	25 days
Contacted by navigator case manager	within 3 days	1 day
Follow-up procedure scheduled	within 4 days	1 or less
Receive follow-up procedure	within 5-10 days	8 days
Woman notified of procedure results	within 3 days	3 days
Biopsy scheduled	within 4 days	less than 4 days
Biopsy procedure	within 7 days	7 days
Pathology results	within 3 days	3 days
Referred to Cancer Center	within 7 days	13 days*
Receive first cancer treatment	within 14 days	12 days

<sup>\*</sup> Challenges and barriers affecting outcomes: Co-morbid conditions that needed to be resolved prior to referral to cancer center and start of cancer treatment.

they are followed by the breast navigators from diagnosis through treatment and for five years after the completion of treatment.

#### **Outcome Measures**

Starting in 2007, we began evaluating our navigation program using outcome measures developed by the American

Cancer Society (see Table 1 on this page). At Broward Health, we developed the following outcome measures for our navigation program:

- Patient will be contacted by a navigator within 72 hours of referral (after an abnormal finding)
- Follow-up procedure will be scheduled within 48 hours of patient being

- contacted by the navigator
- Patient will receive follow-up procedure (biopsy, ultrasound, etc.) within 5-10 days (after initial call from navigator)
- Patient will be notified of procedure results within 72 hours (after the procedure has been carried out)
- All biopsies will be scheduled within 48 hours (after abnormal finding)
- All biopsy procedures will be completed within 7 days (after the patient is notified of an abnormal result of the diagnostic mammogram or ultrasound)
- Pathology results will be communicated to patient within 72 hours (after biopsy has been performed)
- Patients with a positive cancer finding will be referred to Broward's Comprehensive Cancer Center within 7 days
- Patients will receive first cancer treatment within 14 days after referral to the patient navigator.

Outcomes from the breast navigation program are excellent (see Table 1), and the program helped keep the cost of care down for patients who qualify for navigation services. Broward Health's Administration is currently reviewing the Breast Navigation Program with the goal of continuing the program and expanding navigation services to all cancer patients.

Pia Delvaille is an Advanced Practice Registered Nurse in the Comprehensive Breast/Cancer Center at Broward Health-Broward General Medical Center. Pia has worked in oncology for 25 years.

#### References

<sup>1</sup>Broward Health. Breast Cancer Navigator Program. Available online at: http://www.browardhealth.org/?id=196&sid=2. Last accessed 03.04.09.

<sup>2</sup>Broward Health. Avon Foundation Awards Grant to Broward Health Breast Cancer Patient Navigator Program. Available online at: http://www.broward-health.org/news/?sid=1&nid=119. Last accessed 03.04.09.



#### BREAST CANCER PATIENT NAVIGATION PROGRAM INDICATORS<sup>1,2</sup>

DATE OF BIRTH/			_ MEDICA	ID/SOCI	AL SEC	CURITY NUMBI	=K				
			AGE RACE/ETHNICITY								
PRIM	ARY LANGUAGE			EMERGENCYCONTACT							
BREA	ST CANCER PROVIDER: B	CC CCC 1	NBMC CO	C PCP				(	CM		
	CASE OPENED/_										
PRE	VENTATIVE CARE MONIT	TORS: Co	ntinuity	, Patient Pa	rticipat	ion, Ef	ficacy and App	propriaten	ess o	f Care	
01.	FIRST VISIT										
	Date of last mammogram: Date of biopsy:					Date	of last ultrasou	nd:			
	1 <sup>st</sup> visit date:	<withir< td=""><td>n 2 weeks</td><td>s: Yes</td><td>No</td><td></td><td></td><td></td><td></td><td></td></withir<>	n 2 weeks	s: Yes	No						
	Negative/positive biopsy:					Breas	st cancer stage	•			
						Provi	der seen at 1st	visit:			
02.	BREAST CANCER CARE/	SURGEO	N								
	Visits:			Date:							
03.	PROVIDER OF TREATME	NT									
	Hospital:					Admit date:					
	Name:						Discharge dat	te:			
04.	TREATMENT DATA										
	Surgery: Yes	No	Date:		Procedure:						
	Type of treatment:	Chemo:	Radiati	on:	Othe	er:	Date	of treatme	nt:		
05.	FOLLOW-UP DATE FOR NEXT PRIMARY CARE PROVIDER										
	Name:										
	Date of appointment:										
06.	FOLLOW-UP DUE DATE	FOR NEX	(T MAMI	MOGRAM							
	Provider:		Results	:			Date:	Seen:	Yes	s No	
07.	PSYCHOSOCIAL STATUS										
	Certification date:					Appr	oval date:				
	Federal poverty level:						Date:				
	Type of transportation:							riend/Famil	<b>γ</b> :		
	Distance to treatment cen	ter:			Fami	ily supp	oort:				
08.	COMMENTS:										
09.	CHECKLIST: (Case manag	er to initi:	al or mark	- N/Δ)							
00.	Gilda's Club		ai Oi iiiaii	X 1 1 / / / /	Fo	ducatio	nal materials				
	American C		ciety				transportation				
	Childcare		·				essation classe				
	Social Work Educate on		If over		Co	ounseli	ng: Smoki	ng Ger	netic	Nutrition	
<u> </u>	Substance a			th							
	Physical the				Ca	ase clo	sed letter				

<sup>1</sup>Breast Cancer Patient Navigator Program Indicators worksheet/tool to be placed in internal DSM case file upon opening of each case. Tool to be retained in the patient's internal DSM case file. This tool should not be placed in enrollee's medical record. <sup>2</sup>Completion of Breast Cancer Patient Navigation Program Indicator's worksheet done from the following data sources: documents faxed from provider's office, information obtained telephonically from provider's office, PCP provider office or primary care center, and Breast Cancer Center medical record.



### BREAST CANCER PATIENT NAVIGATOR PROGRAM REFERRAL FORM/INTAKE SUMMARY

FAX TO:		
DATE:		
TO: Breast Cancer RN Nurse Manager:		
☐ Breast Cancer Social Worker:		
REFERRED BY:	PHONE:	
	FAX:	
CRITERIA FOR REFERRAL:		
<ul> <li>Uncompensated care patient with a minimum of a pos breast cancer</li> </ul>	itive mammogram or newly diagnosed v	with
■ Patient must be aware of her most current diagnostic	esults and/or mammogram status	
☐ CHECK BOX IF PATIENT IS AWARE OR HER POSITIVE (+	) MAMMOGRAM, BIOPSY, DIAGNOSIS	S, ETC.
Patient Name:		
Primary Care Provider:		
Social Security Number:		
Phone Number:		
Address:		
Site of appointment:		
Next appointment:		
Date of Breast Cancer Diagnosis:	_ Intake Form Attached: Yes	No
Other Pertinent Information:		

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#### TRACKING TOOL-BREAST CANCER NAVIGATION

PATIENT NAME:		ID NUMBER:							
DATE ENROLLED:/		DAT	E DISEN	ROLLED	:	_/			
MR#									
		I	I		I	T		T	
Positive Mammogram	Date	Date	Date	Date	Date	Date	Date	Date	Date
Enrollee contacted									
Positive mammogram/provide educational materials									
Schedule follow-up appointment									
Attend appointment with patient (per patient request)									
Medical records reviewed (results within 72 hours)									
Resolution									
Positive Breast Cancer									
Positive breast cancer diagnosis/ provide educational materials									
Schedule breast cancer treatment									
Nutritional education/referral									
Monitor lab results									
Family education and support									
Refer to support groups									
Cultural/language preferences in educational materials									
Interventions: Forms (F), Childcare (C), Transportation (T)									
Interventions: Eligibility (E), Financial (F), Caregiver (CG)									
Communicate with other disciplines									
Case manage chronic health conditions									
Resolution	1	1		1	1	1			1



## BREAST CANCER NAVIGATOR PROGRAM PATIENT SATISFACTION SURVEY

You are enrolled in the Breast Cancer Navigation Program at Broward Health. With your participation, we can help you to manage your breast cancer diagnosis and treatment and help you to live a healthy lifestyle.

Please answer these questions for us. The results of the survey will be used to improve our services to you.

	Excellent	Very Good	Good	Fair	Poor	Does Not Apply
How well did the Breast Cancer RN Navigator and/or Social Worker explain the purpose of the Breast Cancer Program to you?						
Did the program help you understand your breast cancer diagnosis and treatment better?						
3. Were the educational materials and/or community resources provided to you helpful?						
4. How well did the Breast Cancer RN Navigator and/or Social Worker Program help you to better understand Broward Health's healthcare system?						
5. How would you rate the care and concern provided you by the Breast Cancer RN Navigator?						
6. How would you rate the care and concern provided you by the Breast Cancer Social Worker?						
7. How would you rate the Breast Cancer Navigation Program overall?						
COMMENTS						
What did you like best about the program?						
Other comments:						



#### **BREAST CANCER NAVIGATION PROGRESS NOTES**

Date of Initial Mammogram:	
Results:	
Identified Barriers/Concerns:	
Plan of Care:	
Resolution and Date:	
Notes:	
Breast Cancer Navigator Case Manager:	
Date:	
	ADDRESSOGRAPH
	Patient Name:
	MR#
	Date of Birth



#### **BREAST CANCER NAVIGATOR CONTACT LOG**

Date	Patient Name	Type of Contact	Action	Follow-up

### **Outcome Measures Tool**



This tool can help your organization identify outcome measures for your patient navigation program. Keep in mind, measures will be specific to individual programs.

#### PATIENT SATISFACTION

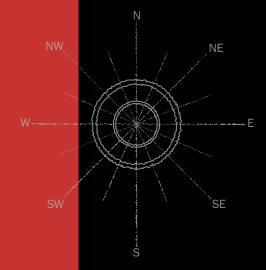
- 1. Patient satisfaction score prior to implementation of navigation services (baseline score).
- 2. Patient satisfaction score 6-12 months after navigation program has unrolled. Continue to monitor scores on an ongoing basis.
- 3. Number of patients leaving the cancer center for treatment elsewhere prior to implementation of navigation services.
- Number of patients leaving the cancer center for treatment elsewhere 6-12 months after navigation program has unrolled. Continue to monitor scores on an ongoing basis.
- 5. Number of patient referrals prior to implementation of navigation services.
- Number of patient referrals 6-12 months after navigation program has unrolled. Continue to monitor scores on an ongoing basis.
- 7. Patient satisfaction with navigation program. Continue to monitor scores on an ongoing basis.

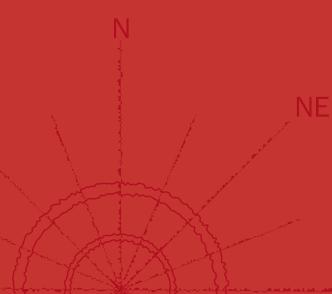
#### PATIENT ENCOUNTERS

- Time to diagnostic mammogram BEFORE and AFTER implementation of navigation services.
- 2. Time to needle biopsy BEFORE and AFTER implementation of navigation services.
- 3. Time to diagnosis BEFORE and AFTER implementation of navigation services.
- 4. BEFORE and AFTER implementation of navigation services, the time to initial treatment from: a) Initial visit, b) diagnostic mammogram, 3) diagnosis.
- 5. BEFORE and AFTER implementation of navigation services, the time from diagnosis to consult with: a) breast surgeon, b) plastic surgeon, c) medical oncologist, d) radiation oncologist, e) genetic counselor.
- 6. Time from OR to chemo/radiation BEFORE and AFTER implementation of navigation services.
- 7. Number of referrals to: a) navigator, b) genetic counseling, c) nutrition, d) social work.
- 8. Number of underserved BEFORE and AFTER implementation of navigation services.
- 9. Number of unavoidable admissions/ER visits BEFORE and AFTER implementation of navigation services.
- 10. Length of hospital stay BEFORE and AFTER implementation of navigation services.

#### PROGRAMMATIC COMPONENTS AND PERFORMANCE IMPROVEMENT

- 1. Track tumor conference recommendations based on guidelines (e.g., NCCN, ASCO).
- 2. Create standing order sets by disease site and measure use of tools.
- Track percentage of patients provided with educational materials/information, BEFORE and AFTER implementation of patient navigation services.
- 4. Track percentage of patients given information on clinical trials and monitor percentage of patients put on clinical trials.
- 5. Create site-specific navigation programs.
- 6. Establish a Patient and Caregiver Advisory Committee.
- 7. Develop marketing materials and measure physician referrals BEFORE and AFTER implementation of navigation services.
- 8. Establish survivorship program and measure patient satisfaction.
- 9. Develop end-of-treatment celebration and measure satisfaction.
- 10. Create support groups and other educational programs and evaluate.





**Association of Community Cancer Centers** 

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