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Breast Cancer Navigation, Our Experience at Avon Breast Center at Hopkins

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Background

The concept of patient navigation was founded in 1990 by Dr. Harold Freeman at Harlem Hospital Center in New York City. His program was an intervention to address late stage breast cancer presentations among minority and poor women in the Harlem community. Navigators were utilized to work with low income patients or with populations that did not tend to get the medical care they needed. Patient navigation focused on identifying and eliminating barriers to care that could result in delays by timely cancer screening, diagnosis, and treatment.¹ Most navigators were non-healthcare professionals, who were members of the community and were trained to provide culturally sensitive care coordination and disease management principles to improve access to care for underserved people.¹ Dr. Freeman's initial program demonstrated that patients with suspicious cancer screening findings were significantly more likely to complete their diagnostic evaluation in a timely fashion when paired with a navigator.²

Due to the success of the Harlem Hospital model, patient navigator programs have become established in many healthcare centers throughout the United States. What began as a pioneering program was recognized nationally in 2005 when the Patient Navigator, Outreach and Chronic Disease Prevention Act was signed into federal law. This

program funded patient navigation demonstration sites throughout the United States and was created to help ensure patients with cancer received high quality coordinated care. Since then, patient navigation has shown repeatedly to improve rates and timeliness of follow up cancer screening abnormalities in various populations.³

Over time, patient navigation programs have evolved to encompass broader goals. Many healthcare facilities have turned to nurse navigators to avoid problems with care coordination, patients getting lost to follow up, and to help improve quality of life and overall patient satisfaction. The navigator functions as an advocate for patients, educates patients on the disease and treatment options, and links patients with resources that will support them to maintain or improve their quality of life and to complete their cancer treatment. The navigator also facilitates communication and acts as a liaison with the healthcare team on behalf of the patient. Studies have highlighted the role of nurse navigators in several areas, including time to diagnosis and appropriate treatment, effect on mood states, satisfaction, support, continuity of care, and costs.⁴

Our experience

Our Breast Center is on the Johns Hopkins Bayview Medical Center Campus, a member of Johns Hopkins Medicine, and located in Baltimore, Maryland. The Breast Center offers comprehensive diagnostic services including mammography, ultrasound, and breast MRI. In addition to screening and diagnostic testing, treatment services available include breast surgical oncology, plastic surgery, medical oncology, high risk clinic, and follow up/survivorship. Other specialty services, such as radiation oncology, clinical trials, and genetic

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counseling, are coordinated throughout campuses located within the Johns Hopkins Health System.

The Breast Center serves North and Southeast Baltimore City and County. This area includes a population which is predominately white/non-Hispanic (70.2%), black/non-Hispanic (13.2%), and Hispanic (11.4%). Almost 25% of the population are uninsured. The major causes of death for residents in this area are heart disease, cancer, and stroke. We do not limit our services to our primary catchment area. We offer many clinical programs that serve patients regionally, nationally, and internationally. Many patients seek our services for second opinions, diagnostics, and treatment planning after an abnormal finding or a new breast cancer diagnosis. However, many of our community benefit efforts are targeted to the communities we consider our neighbors where many residents are considered medically underserved.

Prior to the start of our navigation program, patients had to manage their way through the fragmented healthcare delivery system on their own. After an abnormal finding on breast imaging or a breast cancer diagnosis, many patients were left to schedule multiple appointments for diagnostic tests and specialty consultations over several weeks and across multiple campuses. To complete a course of care some of our patients may need to go to three different clinical sites. This process can be overwhelming, especially for our underserved population, which resulted in missed appointments and delays in care.

There are other system and social barriers that can make it difficult for many women to receive timely care or complete breast cancer treatment. Some of these barriers include financial burdens related to the cost of treatment, employment conflicts, lack of social support, differences in language, transportation issues, and emotional distress and fear. Some women also face cultural barriers to getting timely care. People in Latino and African-American ethnic groups are less likely to get healthcare and may mistrust the healthcare system.⁵ A patient's culture may also influence the treatments they are willing to receive.

Navigator Roles & Responsibilities

Our patient navigation program is a system which is centered on the breast cancer nurse navigator. The navigator is charged with overseeing the movement of a newly diagnosed breast cancer patient throughout the healthcare system. The position is staffed by an experienced oncology nurse who has knowledge regarding all breast cancer treatment modalities. She is located within the Breast Center where she is available to meet with patients at the time of an abnormal breast finding or at their initial visit after a new diagnosis of breast cancer. The navigator is tasked with being highly organized and

skilled at coordinating multiple appointments from initial work up to treatment completion, and the ability to effectively communicate with multiple providers.

The navigator works closely with the Breast Center Access team. This team schedules all new patient appointments for the Breast Center. Once patients are referred for new appointments, the access team contacts the patient, works to obtain any outside records, and then sends this information to the navigator. The navigator reviews patient records, such as breast imaging and pathology, prior to the initial appointment and coordinates scheduling, additional records acquisition, and identifies the need for specialty appointments.

The navigator sees all newly diagnosed breast cancer patients with the breast surgeon. After each visit, she will meet with the patient one on one with her family members to review pathology, summarize the treatment plan, assess the patient's understanding, and provide additional education. During this initial visit, the navigator will also assess for potential barriers to care. She will connect patients with available community resources which can include coordinating transportation, bridging cultural and linguistic barriers, and connecting patients with financial support services. Each newly diagnosed patient is also screened for distress using the NCCN distress thermometer, and provided with information on support programs or referred to appropriate counseling services as needed.

Multidisciplinary Care

The navigator coordinates patient care throughout the continuum in collaboration with the multidisciplinary team. As the patient moves from one discipline to the next, the navigator streamlines patient appointments to ensure timely service from diagnosis to the initiation of treatment. This is accomplished by coordinating appointments for diagnostic testing and facilitating timely appointments for consults and support services as appropriate. The navigator tracks patients across the cancer care trajectory, evaluates for delays or missed appointments, and provides interventions to promote completion of treatment.

Patients with complex cases, such as triple negative or Her2 positive breast disease, benefit from a Breast Multidisciplinary Clinic. The navigator oversees this clinic, coordinating appointments so appropriate patients can be seen by the entire team in one visit and leave with a treatment plan. This model decreases fragmented care and can shorten the length of time to begin neo-adjuvant therapy by weeks. The navigator meets with patients and their family members at the completion of their visit to make sure the patient understands the plan of care. The navigator will provide education and referrals to support services as needed.



Other Program Components

Our Navigation Program also serves as a resource for community educational events, such as health fairs, screenings, symposiums, and lectures as well as hospital staff education. The nurse navigator provides educational programs on breast health and breast cancer screening and equips individuals and groups with needed resources. The nurse navigator collaborates with the Community Relations department which has connections with a number of community organizations and religious congregations to promote breast health education in the surrounding neighborhoods.

Our Navigation Program includes a breast cancer survivors program. Many breast cancer survivors often face physical, emotional, social, and financial challenges as a result of their diagnosis and treatment. Our survivors program is facilitated by our breast navigator and is open to any breast cancer survivor no matter where her cancer care is received. Meetings are held monthly and include guest presenters discussing a variety of topics related to survivorship issues. Caregivers are also welcome to attend.

Program Evaluation

Our patient navigation program was initiated in August 2013 after receiving funding from the AVON Foundation for Women with the goal to optimize care for patients diagnosed with breast cancer. It was our hypothesis that a nurse navigator who will meet with newly diagnosed patients would reduce patient depression/anxiety, lessen the elapsed time from diagnosis to treatment, improve quality of life, minimize barriers, and enhance patient-centered quality of care. Our program is measured by the number of patients who receive one on one education, the elapsed time from initial visit to surgery/systemic therapy, the number of support services offered (childcare assistance, transportation, financial assistance, etc.), and the number of consumers reached through community outreach. We also measure patient distress before and after the initial visit with the nurse navigator utilizing the NCCN distress thermometer. Other metrics measured include patient satisfaction scores, support group evaluation forms, reduction of no shows, improved patient flow, and increased physician satisfaction.

The navigator is responsible for maintaining program metrics and quality indicators for review by the Breast Center Director. The navigator utilizes a navigation database to track program progress and services utilized by patients. The navigator routinely meets with the breast center director to discuss standards and policies, system barriers uncovered, and goals of the breast program. The director has the authority to affect system level change to ensure the program's continuous commitment to providing

high quality care for patients diagnosed with breast cancer.

Over the past two years patients were provided individualized education and a large portion of patients utilized navigation services such as transportation and financial assistance, support group/counseling referrals, and material support. The navigator role has also allowed us to increase community outreach efforts. The Breast Center staff participated in several events last year providing education on breast health and cancer screening to surround community members.

Conclusion

Our Nurse Navigation Program is focused on providing high quality breast cancer care for patients receiving treatment within our health system. Our goals are centered on removing barriers, guiding patients through the system, and improving treatment completion. Core components of our navigation program include patient education, identifying and eliminating barriers, and care coordination to ensure timely service and adherence to care. Navigation services are designed for newly diagnosed patients, survivors, and those with metastatic disease.

Research has shown that nurse navigators help cancer patients feel more supported and informed, better prepared for the future, and they faced fewer perceived problems.⁶ This article describes the role of the nurse navigator and highlights the functions they serve in enhancing the quality of breast cancer care. Our program description provides a foundation for developing a nurse navigator role within a breast cancer program and identifies measurable program metrics and quality indicators.

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