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The Joint Psychosocial and Nursing Advisory Group to the New Jersey Commission on Cancer Research (NJCCR) was appointed to advise the NJCCR of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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Patient Navigation in Cancer Care

by

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There are a myriad of barriers to cancer prevention, cancer screening and early detection, and cancer treatment among underserved populations. Such barriers include being uninsured or under insured; low education or health illiteracy that may contribute to fears of cancer screening and/or diagnosis; culture, contributing to a lack of trust in the health care system and/or fatalism regarding cancer or presenting language barriers; and other factors such as lack of transportation, child-care commitments, and clinic schedules (Aziz & Rowland, 2002; Breen, Kessler, & Brown, 1996; Brown, 1996; Dohan & Schrag, 2005; Harper, 1993; Lannin, Mathews, Mitchell, Swanson, Swanson & Edwards, 1998; Lannin, Mathews,

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Mitchell, & Swanson, 2002; Lantz, Dupuis, Reding, Krauska, & Lappe, 1994; Richardson, 2004; Wolff et al., 2003). Patient navigation programs seek to reduce disparities by addressing these barriers. In fact, the literature suggests that navigation is associated with improved rates of cancer screening and follow-up, lower clinical stage of presentation, and higher patient satisfaction (Dohan & Schrag, 2005; Freeman, Muth, & Kerner, 1995).

In 1995, Dr. Harold Freeman developed the initial patient navigation program aimed at breast cancer. Community members were used to help others navigate the health care system by addressing barriers to cancer screening, further diagnostic testing, and timely treatment of breast cancer. Navigation included the provision of education and support, as well as with assistance with transportation, child care, and scheduling of appointments. As a result, late-stage breast cancer rates over the next 5 years decreased from 50% to 21% and the 5-year survival rates increased from 39% to 70%. Patients with navigators were found to have higher screening rates, were more likely to follow-up abnormal results, and more likely to obtain and maintain cancer treatment. This initial program targeting "high incidence of late-stage cancer and poor prognostic outcomes of low-income and medically underserved minorities" has served as a model for other navigation programs across the country (Fisher, Sauaia, & Kutner, 2007; Freeman, et al, 1995).

Since the establishment of this first patient navigator program at Harlem Hospital in 1990 (Freeman et al., 1995), there has been over 200 cancer care programs in the U.S. that have implemented some form of patient navigation (Ferrante, Chen, & Kim, 2007). In addition, two bills in the United States Congress in 2003, House Resolution 918 and Senate Resolution 453, proposed support for patient navigators as part of "model programs to provide…prevention, early detection, treatment, and appropriate follow-up care services" for medically underserved patients and populations. Trans-Health and Human Services Cancer Health Disparities Progress Review Group put forth a report identifying patient navigation programs as an integral resource for eliminating health disparities found in cancer. The National Cancer Institute (NCI) in 2002-2003 funded 6 patient navigator programs as part of its Cancer Disparities Research Partnership Program. In 2005, the National Institutes of Health planned to commit an additional $55 million to support research on both the effectiveness and cost effectiveness of patient navigator programs (Dohan & Schrag, 2005).

Amid all of the increasing attention focused on patient navigation in cancer care, what exactly is Patient Navigation? There is no current consensus definition of patient navigation (Dohan & Schrag, 2005; Fisher et al., 2007). Although some sources in the literature define navigation as the provision of a set of services to patients, others define a navigator as someone who specifically addresses barriers to care. The United States Center for Medicare and Medicaid Services (CMS) and the Canadian Breast Cancer Initiative attempted to define patient navigation according to the services provided. Three types of navigation services were identified by CMS: connecting individuals to screening, following patients post-screening, and assisting patients through the course of treatment (Dohan & Schrag, 2005). The Canadian Breast Cancer Initiative focused on treatment services, finding that some navigators proactively direct patients through treatment by scheduling appointments, for instance, whereas other navigators facilitate treatment more subtly by providing information, support, and encouragement (Dohan & Schrag, 2005). However, these service-focused definitions lack specificity because of a myriad of health care professionals that may provide the same or similar services. For example, case managers, advance practice nurses, and physicians also coordinate patient care, provide cancer education, assist with administrative arrangements, or provide social or emotional support to the cancer patient (Bickell & Young, 200; Dohan & Schrag, 2005). In the community, lay or peer advisors and counselors, such as community health workers and community health advisors may also provide navigation-like services

as well (Bird et al., 1998; Dohan & Schrag, 2005; Eng & Smith, 1995).

Another definition of patient navigation emphasizes the navigator's focus on the patient's "perceived barriers" to care. Using this model, navigators primarily play a reactive role by addressing barriers that are usually not identified in advance, but emerge during interactions with patients. Similar to navigators, patient advocates also play a reactive role by trouble-shooting a patient's problems as they arise. However, unlike navigators, advocates are concerned with the healthcare system as a whole rather than delivery of care to individual patients. Community outreach workers, such as lay health educators, typically focus on informing patients about the importance of adherence to a particular healthy behavior, such as colon cancer screening. However, unlike navigators, educators are more proactive in addressing specific barriers, such as lack of knowledge of the benefits of the screening. Social workers and case managers also play a more proactive role than navigators in delivering services to individual patients. However, there is undoubtedly an overlap between the work of patient navigators and other cancer support workers (Dohan & Schrag, 2005). Given the lack of a standard definition of patient navigation, patient navigator activities vary widely from program to program leaving the definition of patient navigation somewhat vague.

Patient navigators build trust with the community they serve to provide one-on-one, culturally appropriate, patient empowering interventions (Fisher et al., 2007). Patient navigators assist to facilitate cancer screening, follow-up for positive cancer screening, and cancer treatment as well as provide education and emotional support and outreach, and assist with tangible needs such as transportation and childcare. Navigator programs in cancer care have expanded and will continue to expand to hospitals and clinics across the country**,** leading to improved cancer outcomes (Fisher et al., 2007).

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Addressing Cancer Disparities through Patient Navigation

by
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Many advances in biomedical and behavioral research have contributed to increased longevity and improved quality of life for many cancer patients and survivors. Despite these advances, some cancer patients have not fully benefited from this progress; particularly the racial/ethnic, poor and underserved communities, as evidenced by their high cancer incidence, mortality and lower survival (Freeman, 2005).

Since the Heckler Report (1985), several major federal initiatives have attempted to define and address disparities in health care including the HHS Cancer Progress Review (PRG). The National Cancer Institute's Center to Reduce Cancer Health Disparities (CRCHD) was initiated in March 2001 with a mission to reduce the unequal burden of cancer in US through research and training.

While some progress has been made in closing the health disparity gap, in some cases, mortality and morbidity rates have increased for minorities, while the rates for whites have declined or remained stable. For example, national trends indicate that black men have higher incidence rates of late stage prostate and colorectal cancer diagnoses in comparison to white men, and black men demonstrate a smaller average decline in prostate and colorectal mortality rates (Ghafoor et al., 2002).

The challenge of providing continuity of care to medically underserved cancer patients with complex health needs in a fragmented healthcare system continues to be a widespread problem in health care and policy. While there are multiple interacting factors that cause disparities, research to date suggest that barriers to appropriate and timely care play a critical role (Dohan & Schrag, 2005; Steinberg et al., 2006). These barriers include low

screening rates; high rates of missed follow-up appointments; cultural histories and experiences that lead to mistrust of healthcare; low levels of health literacy; cost of care; competing health, family and occupational demands; psychological distress; logistical barriers (e.g., transportation); lack of insurance and a regular source of care (Ell, Vourlekis, Lee, & Xie, 2007; Freeman, Muth, & Kerner, 1995; Steinberg et al., 2006).

Patient navigation is an innovative community-based intervention that is patient-family centered to ensure continuity of care, support to cancer patients and families throughout the complex continuum of cancer care. In 1990, Freeman et al (1995) established the first navigation program in Harlem, NY to assist medically underserved patients with follow up after abnormal screening findings. Based on the successes of this early program, several private and federal initiatives were established. In 2002-2003, the CRCHD developed and funded six Patient Navigation Programs (PNP) to "develop effective interventions to reduce cancer disparities by facilitating timely, continuous access to quality standard care for all Americans" (p. 1).

Patient navigators serve many roles that address the psychosocial, cultural, economic and linguistic complexities of patients' life styles and healthcare experiences including: patient advocates for patients with abnormal screening findings; case managers who coordinate appointments with providers to ensure timely delivery of treatment, maintain communication with the patients/families to monitor satisfaction with the cancer care, arranging language translation/interpretation, facilitating financial support, arranging transportation and/or child/elder care, facilitating follow-up services, health education and provide access to clinical trials.

While the role and responsibilities of patient navigators are broadly defined, these programs have been found to be successful in addressing the diverse and changing needs of medically underserved groups. Patient navigation programs have been described as beneficial to medically underserved groups because their services can be tailored to patients' diverse cultural and linguistic needs at varying times in screening, diagnosis and treatment of patients. Flexibility or adaptability of patient navigator programs has been identified as a major strength in meeting the complex needs of underserved groups (Burhansstipanov et al., 2001).

Observational studies suggest that navigation programs have been associated with improved rates of screening and follow-up, higher levels of patient satisfaction and improved levels of trust among low income and medically underserved groups (Dohan & Schrag, 2005; Freeman et al 1995). Only two randomized control trials have been published to measure the effectiveness of patient navigation programs. These studies found patient navigation to be effective in improving follow-up adherence rates, time to diagnostic resolution, decreasing anxiety and increasing satisfaction among low income black and latino women with abnormal mammograms (Ell et al, 2006; Ferrante et al, 2008). However, the small sample size of these studies limits the generalizability of the results to other groups of medically underserved patients and other cancer sites. Future studies with larger sample sizes of men and women, in other settings and cancer sites are needed to evaluate the true effects, specify the mechanisms of success and cost-effectiveness of navigation programs (Dohan & Schrag, 2005).

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ANNOUNCEMENT

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Patient Navigator Program at UMDNJ-New Jersey Medical School

by

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In 2005, with support from the Susan G. Komen Breast Cancer Foundation-North Jersey Affiliate, Dr. Jeanne Ferrante, family physician, pioneered a breast health patient navigator program at UMDNJ-New Jersey Medical School/The University Hospital in Newark, New Jersey. The "Sister-to-Sister Navigator Program" is a breast cancer outreach and patient navigation program serving predominantly African-American women in Newark and its surrounding communities. The breast health navigator educates and empowers women and helps them to overcome financial, communication, medical system and emotional barriers in obtaining breast cancer screening, diagnostic, treatment, and follow-up services.

The patient navigator is an African-American woman with a bachelor's degree in social relations with previous experience as a youth advocate, habilitation counselor, and breast cancer support group volunteer. An educated and experienced person was chosen who would be knowledgeable about the hospital system and could help translate medical terminology and facilitate communication to the patients. Training prior to initiation of the project included education on breast cancer screening and diagnosis, public speaking skills workshop, and orientations and observations with the mammography van unit, radiologists, breast surgeons, oncologists, social workers, and financial assistance personnel. Contacts were made with other community organizations providing breast cancer outreach and support. Ongoing mentoring and supervision with the oncology social worker and Dr. Ferrante is provided, and ongoing training is obtained through conferences for health and social service workers and breast cancer symposiums.

The patient navigator outreaches to approximately 1800 minority women per year in the community at health fairs, churches, senior centers, beauty salons, laundromats, pharmacies, supermarkets, housing projects, and other community-based organizations to provide education on breast cancer screening and clinical trials. Knowledge of women attending educational sessions have improved with scores on pre- and post-presentation quizzes increasing from 40% correct to 90% correct. Women without insurance are referred to the New Jersey Cancer Education and Early Detection program for free screenings. In addition, the navigator recruits, trains, and supervises approximately 20 lay women per year to be peer volunteers. In 2007, 30 active volunteers outreached to 329 women, providing education on obtaining mammograms.

The patient navigator also performs navigation services to approximately 85 to 100 women per year with suspicious mammograms (American College of Radiology Breast Imaging and Reporting Data Systems [BI-RADS]) of 4 or 5) and approximately 20 to 30 women per year with breast cancer diagnosis. Through one-on-one contact, she makes sure the women obtain timely follow-up and needed diagnostic services, and their fears about diagnosis and treatment are allayed so that they do not "fall through the cracks." Navigation activities include psychosocial and emotional support, assistance with getting appointments for diagnostic testing and treatment, rescheduling missed appointments and accompanying patients to appointments, assistance in filling out insurance and charity care forms, explaining technical medical terminology, encouraging compliance with treatment, arranging for housing, transportation or child care, helping patients obtain wigs, prosthetics, medications, and bedding supplies, and connecting patients to support groups. She also personally outreaches to patients who are not compliant with breast cancer treatment by visiting their homes, providing encouragement and support, and helping them to resume their treatments.

The "Sister to Sister Navigator Program" has been evaluated by a randomized controlled study, which demonstrated its effectiveness in decreasing time to diagnosis after a suspicious mammogram, decreasing patient anxiety, and increasing patient satisfaction (Ferrante, Chen, & Kim, 2008). Women in the patient navigator group had shorter times to diagnostic resolution (X = 25.0 vs. 42.7 days; $p = .001$), with 22% of women in the control group without a final diagnosis at 60 days vs. 6% in the patient navigator group. The navigator group also had lower mean anxiety scores (decrease of 8.0 in intervention vs. increase of 5.8 in control group; $p < .001$), and higher mean satisfaction scores (4.3 vs. 2.9; $p < .001$). The success of this project has led to other grants at University Hospital from the Avon Foundation and the Susan G. Komen for the Cure, North Jersey Affiliate using patient navigation to help increase minority women enrollment in breast cancer clinical trials. The long-term goals of this program are to increase the percentage of women with breast cancers diagnosed at early stage at University Hospital, increase survival, and decrease mortality, thereby reducing the disparity in breast cancer burden suffered by African-American women of Newark.

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The Role of the Patient Navigator

by

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While the term "Patient Navigator" has permeated the medical field over the past decade, patient navigators have been in the health field for many years. More commonly known as nurses, social workers, doctors or patient advocates, these familiar members of the medical team routinely

help patients chart their course from diagnosis through treatment and into survivorship. Still, in recent years, research has revealed major gaps, or unequal patterns of service delivery, triggering a call to more formally initiate the role of a patient navigation. The National Cancer Institute, among other national organizations, has sponsored programs in an effort to develop interventions to reduce the time of delivery of standard cancer services, cancer diagnosis and treatment after screening.

The cry for clarity and assistance is not surprising given the complexity of insurance claims, rigidity of HMOs, spectrum of specialists and the ever-expanding number of resources on the internet. Too often, cancer patients struggle to navigate the maze of financial, medical and emotional issues alone. Fragmentation of the health care system presents obstacles and can prevent a person from receiving quality care or timely access to resources. Additionally, this challenge can create disparities in health care delivery across the population, particularly for lower social-economic and education levels.

Patient navigation has increasingly gained recognition as an important, if not vital, aspect of quality cancer care. A patient navigator provides individualized assistance throughout all stages of the cancer experience from diagnosis to post-treatment survivorship. The role of the patient navigator ranges from providing education to information referral to guidance with negotiating the health care system. A patient navigator can introduce a patient to resources for financial assistance or psychosocial support. They often have experience advocating on behalf of patients and can help to identify patient needs, particularly important when many patients understandably “don’t know what they don’t know”. With guidance to help patients with the logistics of scheduling appointments to the coordination of travel arrangements, patient navigators play a role in quality assurance by helping to eliminate barriers to treatment, bolstering compliance and adherence. A patient navigator may also be the trusted person a patient leans on for reassurance and emotional support.

The specific tasks of any given patient navigator may vary and differ from program to program, but the goal of most patient navigation programs is to provide a single point of reference to organize the overwhelming nature of a new cancer diagnosis. Patient navigation programs have become a burgeoning field popping up in the health care system, the private sector and community centers. Still, patient navigation is more often informal, casual, undocumented and uncompensated, provided by nursing staff, social workers, volunteers or trained survivors.

Simply put, the role of the patient navigator is to establish an ongoing relationship with a patient. A patient navigator not only provides patients with the information and resources necessary for their cancer journey, but they listen, work to understand the unique concerns of the person sitting across from them, and insightfully anticipate the needs patients may have as they walk this unfamiliar and unexpected path.

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