How Patient Navigators Can Help You Get Through a Cancer Journey

Patient navigators improve patient satisfaction, speed effective care, reduce health disparities and save money. Why aren't there more of them?

December 9, 2024 By Bob Barnett

One September morning in 2010, Brenda Guthrie, an accountant in central North Carolina, stopped to have breakfast at her favorite café, Liberty Family Restaurant in Lewisville, before work.

It may have saved her life. She recognized oncology nurse Sharon Gentry, RN, from a newspaper article. Gentry, who has served on the leadership council of the Academy of Oncology Nurse & Patient Navigators (AONN+) and currently is editor-in-chief of the Journal of Oncology Navigation and Survivorship, had started the area's first breast cancer patient navigation programs in nearby Winston-Salem in 2000.

"You're that breast cancer lady, right?" asked Guthrie, who proceeded to describe her symptoms. It was a lucky cup of coffee. Gentry made an appointment for her that afternoon with a breast cancer surgeon. A biopsy revealed inflammatory breast cancer, an aggressive variant that can spread rapidly. Guthrie started chemo that month, had surgery in February 2011 and started radiation in May. She's been cancer-free ever since.

Gentry supported Guthrie through each step. "Sharon was a wealth of information for my every question, guided me to where I needed to go, told me what to expect. When I was terrified of radiation, she told me I'd spend more time taking my clothes off and putting them back on than during actual radiation. She helped relieve stress and anxiety, gave me calmness. I don't know how anyone can get through a cancer journey without the blessing of a nurse navigator."

Sharon GentryCourtesy of Sharon Gentry

A cancer diagnosis can be daunting, overwhelming and confusing, and care may be fragmented across many providers. An oncology navigator can help you understand what's happening and overcome any barriers to getting the best care. "An oncology navigator connects with a patient, establishes a trusting relationship and addresses whatever needs the patient has," says Richard Hoehn, MD, a surgical oncologist at University Hospitals Cleveland Medical Center, who coauthored a 2024 systematic literature review of oncology navigation.

Whether they're a nurse, social worker or a nonclinical community member, a patient navigator gets special training and accreditation. AONN+ provides separate certification programs for nurse navigators and for nonclinical patient navigators. Many academic cancer centers also offer certification. "Studies across the board show that navigators help cancer patients have better outcomes, and they actually save or make money for hospital systems," says Hoehn, whose review found that 70% of studies noted a significant improvement in treatment completion among patients, and 87% of patients reported greater satisfaction. "If you deploy navigators to get patients screened for breast cancer, prostate cancer or colorectal cancer, screening rates go up," he says. "Having a navigator after diagnosis improves the timeliness of treatment, which improves outcomes and improves well-being, quality of life—the stuff that is so important to the patient." Given all this evidence, says Hoehn, "I just can't wrap my head around why we're not doing this more."

A Powerful Equalizer

While oncology navigation is an effective tool for nearly anyone facing cancer's complexities, it has proved to be particularly powerful for addressing one of the most vexing aspects of cancer care—health disparities among racial, ethnic and Indigenous minorities, rural and inner-city populations and the uninsured. Indeed, that's its origin story.

In 1990, frustrated that so many of his patients presented with advanced disease, Harold Freeman, MD, a surgical oncologist in Harlem since the late '60s, set up the nation's first patient navigator system. Through improved screening and timely treatment, five-year-survival rates for breast cancer increased from 29% to 70%. Later, at the National Cancer Institute, he showed in a 2012 study of people with breast, cervical, prostate and colorectal cancers that navigation "shortens the critical time from abnormal findings to diagnosis and treatment in poor populations."

"Harold Freeman really understood that the needs of the community matter, whether that is uninsured communities of color or rural and frontier communities," says Andrea Dwyer, director of the Colorado Cancer Screening Program at the University of Colorado Cancer Center and chair of the National Navigation Roundtable. "Not everything looks the same for all patients."

Andrea DwyerCourtesy of Andrea Dwyer

In 1994, Linda Burhansstipanov, DrPH, a Cherokee woman who'd been working in public health since 1971, showed how the model could work in a very different population—also extremely poor but geographically and culturally isolated: American Indians. She trained American Indian "native sisters" and one "native brother" as navigators to work in Los Angeles and Denver to improve cancer screening and treatment; in later years, non-native navigators were added. "One of our biggest findings was that you need to have someone from the community, respected by the community, who understands the culture and the challenges. It's so hard to say, 'I can't do this alone—I need help.' Navigators create a safe place where you can do that, and that is phenomenally powerful."

Appropriate cancer care is often hundreds of miles away, so she helps with transportation, lodging and access. But there are cultural barriers too. Some native individuals consider cancer to be a death sentence—partly because mortality actually is so much higher in this community. “People say, ‘I thought if you had cancer, it meant you were dying, but now I see people being happy, laughing, living their life—they’ve experienced cancer, and now they’re a thriver,’” says Burhansstipanov. Celebrating survivors, she adds, makes it easier to motivate the newly diagnosed to overcome barriers to care.

Linda BurhansstipanovCourtesy of Linda Burhansstipanov

Sydney Roberts, community program manager at The Gathering Place in Beachwood, Ohio, a suburb of Cleveland, knows the power of community-based patient navigators. The Gathering

Place offers services to individuals, families and caregivers free of charge. Often, Roberts's clients have limited access to resources, and many, like Roberts, are Black. She helps them with whatever is standing in the way of getting the best care, whether it's transportation, childcare, paying for utilities or groceries, life insurance, legal issues (like power of attorney), wigs for hair loss due to chemotherapy, medical library research and referrals to medical or mental health professionals. "We connect people to resources that they may not know exist," she says. "We stand in the gap." Roberts recently helped a client in recovery from substance use disorder who was diagnosed with Stage III breast cancer get a $1,000 grant from the Breast Cancer Fund of Ohio, "which was enough to get her through the hump of being down from work because of her surgery, and now she's back to working part-time. She's had her ups and downs, but she's doing OK. It's been a joy to watch."

In Lorain, Ohio, Ana Melendez, a caseworker at El Centro de Servicios Social (in English, "the center for social services"), supports a predominantly Latino community. Her own parents hail from Puerto Rico. Melendez works with patients facing various cancers, including lung, colon, breast and cervical cancer, as well as leukemia. Many of her clients have limited English proficiency, and some are undocumented, which makes them anxious about official interactions. She meets them at the hospital to guide them through the process, arranges for interpretation services and consistently follows up. "If I see that someone needs additional support, I'll reach out more," she says.

Sydney RobertsCourtesy of Sydney Roberts

Further research has demonstrated the power of navigation to overcome health disparities. One study analyzed minority patients with aggressive non-Hodgkin B-cell lymphoma, who often have poorer outcomes compared with white people. “There was thought in the medical community that there might be a genetic rationale,” says study coauthor Kris Blackley, RN, director of patient navigation at the Atrium Health Levine Cancer Institute in Charlotte, North Carolina, which employs 38 full-time nurse navigators. “But when we looked at our institution, minorities—85% of whom had navigation—had equal outcomes, even though more white patients had insurance. The study concluded: “Providing equal access to care and availability of an active nurse navigation program may overcome racial health disparities.”

The Power of Nursing

While navigation is particularly powerful for underserved populations, it is clearly beneficial to the broader population of people facing cancer, research shows. Some institutions offer it to every patient soon after diagnosis.

Within medical institutions, the people trained in navigation are often social workers or nurses. Social workers are already trained to provide resources and support, so training them to be navigators makes good sense. Nurse navigators in particular bring more clinical expertise. “Nurse navigators can focus on clinical aspects to make sure the patient’s care is coordinated so that they get expedited treatment,” Blackley says.

“I call her an angel,” says Mary Rasmussen, 74, a caterer in Charlotte, describing Delois DeShazo, RN, the oncology nurse navigator who helped her through her breast cancer treatment in 2018. She underwent almost a year of treatment—chemotherapy, radiation, then lumpectomy surgery, followed by reconstructive surgery; she is now on adjuvant medication. She met her navigator at her first meeting with the surgeon. “That first day, Delois came over, held my hand, gave me a hug and said, ‘Don’t worry, we are going to get through this.’ She gave me her email, cell phone number, told me to call anytime.”

DeShazo worked with Rasmussen’s occupational therapist to help her overcome insurance issues in order to obtain a “bubble suit” to treat the lymphedema—swelling in the body—caused by lymph node removal. One time, after being hospitalized, Rasmussen experienced problems with her post-surgical draining tube. She called her navigator at two in the morning and left a message. “I said, ‘It’s not an emergency. Call me in the morning.’ I hung up, and 30 seconds later, my phone is ringing. I said, ‘Do you not sleep?’ She said, ‘When my patients need me, I’m there. I have a direct line to the whole cancer staff, so I can get an answer for you immediately.’”

Expanding Reach

While recognition of the benefit and effectiveness of patient navigation is growing among cancer hospitals, insurance companies and government, “only a small minority of hospitals across the country have navigators dedicated to assisting the cancer patients with the greatest need—it usually just falls to the care team,” says Hoehn, who is helping to set up a Cleveland-wide navigator network and demonstrating its cost-effectiveness.

There’s a strong national movement to expand oncology navigation. Beginning in January 2024, Medicare provided specific codes to allow reimbursement; a few states have extended codes for Medicaid too. In March 2024, the Biden administration’s Cancer Moonshot program announced that seven major health insurance companies will pay for navigation services, and 40 comprehensive cancer centers and community oncology practices have implemented the new codes.

“Once Medicare starts covering a service or benefit, it’s more routine, and Medicaid and commercial insurance start reimbursing more routinely as well,” says Dwyer. Less reliance on grants, which are usually time-limited, means more permanent hires, better wages and more sustainable programs. But Dwyer believes much more work is needed to make navigation universally available, especially for the underserved individuals for whom it offers the most dramatic benefits, many times outside of clinical settings. She’s concerned that better-funded cancer institutions may benefit most from the new reimbursement opportunities because they already have the staff, while smaller community-based cancer centers with the greatest need may not. “We don’t have enough resources for navigation for everyone,” she says. “While we’re getting there, we can’t lose the focus on equity.”

SIDEBAR

Finding Your Navigator

If you have a relatively simple cancer diagnosis, have good insurance, can afford time off, are comfortable researching medical information and have a supportive network of family and friends, you may not need an oncology navigator. But if you are undergoing complicated or challenging treatment, want help understanding what the doctor is saying, have financial or employment or insurance issues, are scared or feel isolated or face any other barrier to getting better, then you may benefit. Here are ways to find help:

Ask at the beginning of care—and when new needs arise. Ask your care team if you can work with an oncology navigator; one may be available but only upon request. “You can ask anywhere along the continuum of your care, ‘Do you have a navigator who can explain this to me?’” says Sharon Gentry, RN, an oncology nurse and navigator. “If they don’t, then ask, ‘Who is the person who’s going to help me through all this? Who’s going to be my single point of contact?’” Many advocacy organizations in the community may also offer navigators who can connect you to local resources as well as national support, Gentry adds. “Even if there is not a formal navigation program, nearly every cancer center offers an opportunity to meet with a nurse or social worker who may be able to informally help you navigate the system.”

Look for online and telephone support. Many nonprofits offer telephone-based services. CancerCare, for example, has “resource navigators,” and the American Cancer Society offers cancer information specialists. Many cancer-specific nonprofits offer similar free services. While not a substitute for a trained oncology navigator, these services can connect you with information and resources to help you overcome barriers.

Be your own advocate. “Ask questions,” says Richard Hoehn, MD, an expert in oncology navigation. “Any cancer program should have some resource to support patients aside from their medical needs. Say, ‘This is what I need—I view it as necessary to completing the treatment you are recommending.’”

For related information, see the article “A Brief History of Oncology Cancer Patient Navigation.”
