Cancer Health™

Navigating Cancer and Barriers, One Person at a Time

Patient navigators provide “good pragmatic help" and much more to cancer patients.

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“It was so scary at first,” said Elizabeth Schalau, of Mill Creek, Washington, who was diagnosed with cancer just before COVID-19 hit in early 2020. “I was being bombarded with all this news, trying to wrap my head around it. I didn’t even know what ‘metastatic’ was.”

Not only was the 54-year-old overwhelmed to learn she had stage 4 (or metastatic) cancer that had spread from her breast to her pelvic bones, she was also dealing with side effects from chemo, pain from the cancer itself and juggling her cashier job with dozens of treatment appointments. When her employer demanded she work night shifts, she was finally forced to quit.

“I was in shock about losing my job and having to be in a doctor’s care,” she said. “I was having trouble walking, panicked about money, so I called Anne who’d introduced herself to me when I was first diagnosed. She helped with financial assistance and directed me to different programs. Having somebody like Anne was a lifesaver.”

“Anne” is Anne Devine, the patient navigator supervisor at Seattle Cancer Care Alliance (now Fred Hutchinson Cancer Center). Devine heads a team whose job it is to help patients navigate the complicated cancer care system. Founded in 2007, the patient navigation program has become an integral part not just of Fred Hutch’s supportive care services, but the institution’s approach to health equity.

“We really want to promote health equity. That’s a real commitment we all have,” said Devine, who’s been with the program for 8 years. “All of us are here because we want to help people.”

Dr. Jay Mendoza, a pediatrician and director of the Fred Hutch/University of Washington/Seattle Children’s Cancer Consortium’s Office of Community Outreach & Engagement, which partners with the navigation team, said the work they’re doing is all part of the Cancer Consortium’s mission to provide better cancer outcomes for everybody.

“Underserved populations often have a very challenging time accessing cancer care at the frequency and intensity it’s needed,” he said. “We’re really interested in helping to close the gaps in care which are often created by our systems. The health care system in general is pretty byzantine. It’s not easy to get through even if you’re coming from within. These navigators do an amazing job of closing gaps, making people feel welcome and making sure there’s a familiar face that patients and their families can turn to for help.”

Relatability and crucial resources

What services do patient navigators provide?

“Good pragmatic help,” Devine said. “People say it’s the logistics that freak them out even more than the cancer. They’re trying to figure out how to do it all and afford it all. The most common issues are transportation and financial assistance, along with insurance coverage, medication co-pays, medical lodging, interpreting services and emotional support.”

Cultural bridging is another area where the navigators make a big difference.

“We help patients communicate with providers when they don’t understand something,” Devine said. “We can be in the room with them. We’re not medically certified interpreters but we’re there to encourage people to self-advocate and ask questions.”

Sometimes that means translating the medical-speak into understandable English and then into another language — the navigation team often uses interpreters, either in person or via phone or video. Other times it’s about knowing important cultural touchpoints.

Patient navigator Ahreum Yang, who is Korean American, works primarily with Asian American and Pacific Islander, or AAPI, populations.

“When I connect with someone from an Asian background, I can offer a level of relatability,” she said. “Having someone that has the same background and cultural understanding makes it a lot easier to create a safe space for families and individuals.”

Knowing a little about a culture also helps understand behaviors that seemingly don’t make sense, like not asking for help.

“I’ve noticed in people with a Korean background there’s not a tendency to ask for too many things,” Yang said. “So it’s important to build trust and ask questions about what they need.”

Navigators also step in when they see a patient struggling. Jennifer Deas, who usually focuses on breast cancer patients, said she recently learned of a patient who was having trouble arranging transportation to and from her treatments.

“There was an expectation that she would call Hope Link [which provides services to low-income people] and set up her transportation,” said Deas, who, like the patient, is African American. “But this woman had throat cancer. In speaking with her, I could understand why it was so difficult. If you can’t communicate, you can’t call and arrange transportation. I told her, ‘I’ve got this. I can do it for you.’”

Navigating cancer and barriers to care

Dr. Harold Freeman, the Harlem surgeon who came up with the idea of patient navigation in 1990, envisioned it as a “community-based service delivery intervention designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care.”

In other words, it provides resources and support services to the people who most need them. But the concept has changed over time, said Dr. Scott Ramsey, a health care services researcher and director of the Hutchinson Institute for Cancer Outcomes Research who’s studied the value of patient navigation in cancer care.

“Freeman started this because in these very underserved populations, people would receive a new diagnosis of cancer, disappear for months or years, then show up again when their cancer was incurable,” Ramsey said. “Freeman figured out they couldn’t navigate the system, so he started the program to help them. It was a lifesaving issue for those folks. Then it morphed into this thing where everybody needed a navigator.”

Soon, he said, every cancer center had something akin to a patient navigator, although their roles could be quite different from Freeman’s model. The term soon began to apply to anyone, from the person who helps you pick out the best health insurance plan on the exchange, part of the Affordable Care Act, to a commercial patient navigator who provides their services for a fee.

“There are nurse navigators, health care navigators and social workers who do similar things,” Mendoza said, speaking of the various programs across the country. “But here at Fred Hutch, we’re trying to bring it home to its original intent — to help those who are underserved and underrepresented in our health care system."

Helping these patients is crucial since they often have worse health outcomes due to barriers to care, Mendoza said.

“Some medical centers have VIP programs, programs for people who fly in on their private jets,” he said. "We’re turning that on its head and recognizing that the true VIPs are those who are underserved.”

In Washington state, that means patients from racial and ethnic populations that are underrepresented in medicine; people from low socioeconomic-status households, LGBTQ+ folks and those who live in rural areas.

Thanks to community grants and other funding, the Hutch’s program has grown over the years from two staff members to seven, with each navigator now assigned to a specific population or segment of patients. Recently, the team has adopted a more proactive model, reaching out to patients to introduce themselves and their services before a need becomes critical.

Navigation staff now includes Devine, who supervises the team and covers patients in general oncology, along with Andrea Suzuki, a Spanish speaker; Chloe Fisher who works in the women's center, along with Deas; John Masembe, who serves Black, African American and African-descent populations; Lenora Starr, who serves Indigenous patients; and Yang, who helps AAPI populations.

A job that takes heart

Much of the work is about being there for people during an extremely difficult time and listening to patients' spoken and unspoken needs. And the work is not easy.

Devine said the patient navigation team sees a lot of suffering, and not all of it due to cancer.

“The social circumstances that people are facing can just be dire,” she said. “The social situations are sometimes harder than the cancer.”

Losing patients is hard, as well. Yang still thinks about a couple who traveled to Seattle from Hawaii for the husband's care. Unfortunately, his cancer was much more advanced than they realized and the man died soon after starting treatment.

“They thought they had a lot more time,” she said. “I ended up helping her get the funeral set up, helping her request the records. It's hard to navigate that process. I was able to make it a bit smoother for her.”

That couple holds “a special place in my heart,” Yang said. It was working with them that she came to understand the importance of what she does.

“That was the moment I realized this role isn't just about helping fill out paperwork or finding resources,” she said. “It's being a cultural navigator too and helping these people get through a really difficult time with a bit more support.”

That support extends to each other, as well. Devine said she is proud of how her team has all pulled together to help patients and one another.

“I don't think any of our team will ever be immune to the compassion fatigue,” she said. “I try to remind my team that as hard as the job is, they're kind of a bright spot for people oftentimes. There's an atmosphere of caring here and I think people really value that.”

Sharing their patient experiences with one other helps, too, Yang said.

“It helps that the other navigators experience the same thing,” she said. “We all remind one another what we're doing is meaningful. We don't have the ability to cure a cancer or give someone a home, but we can make a difference.”

A sensitivity to bias

For Deas, sharing these resources with the community is critical.

“Patients don’t know they have these resources available,” she said, adding that her own uncle, who lived in Tacoma, recently died of throat cancer, which if caught early is often survivable.

Unfortunately, his cancer was misdiagnosed for years.

“With African American men, a lot of things are misdiagnosed,” she said. “It took one smart ER resident to finally figure out he had throat cancer and not a sore throat or bronchitis. By that time, it had spread. He had surgery, but they didn’t get it all.”

After surgery, she said, her uncle developed a lump.

“When I addressed it with his medical team, they finally tested it and confirmed that the cancer was back and it was aggressive,” she said. “My uncle ultimately died. But had he had some of our transportation resources, he might have decided to travel to Seattle for his treatment. He was a proud man and convenience played a major role in continuing his care locally. Patient navigation would have made a big difference in my uncle’s care.”

Deas said experiences like that have prepared her for the work she does with cancer patients today.

“Because of the things I’ve been exposed to, I have more sensitivity to the challenges people are going through,” she said.

But navigating the system for patients is only part of what needs to be done to improve health outcomes, she added.

“Getting people access to care is a good thing for the community,” she said. “But we need to do a lot better with building trust, getting more Black, Indigenous and people of color into our trials and getting our boots in the community. We have to invest.”

Respecting other beliefs

Exhibiting cultural humility and respect is how navigators build trust, she said, whether it’s recognizing cultural practices or respecting family power structures.

“Somebody who doesn’t come from an Indigenous background may not understand the use of ceremonial tobacco or may not understand wanting to try alternative methods to control their pain,” Deas said. “As a team, we need to recognize that there are different ways to get to the solution; you have to respect people’s beliefs.”

And that can sometimes be difficult, she said, recalling one family with an adult daughter with cancer. Instead of speaking directly to the patient, the family requested the doctor share the prognosis and treatment recommendations with the head of the family.

“The grandfather made all the medical decisions for this family,” Deas said. “And at first, the care person on the team was like, ‘I’m not talking to him. She has to make her own decisions.’”

In such cases, patient navigators need to set conventional beliefs aside and respect the family dynamic, Deas said.

“We may not like it and they may not get treatment at all,” she said. “In that instance, this female was scared and she counted on her support system to make the best decision for her. Regardless of how we felt, it was not our decision, it was theirs. Ultimately, the care person was able to talk to the elder and present everything.”

Measuring success, moving forward

Mendoza said the OCOE is currently analyzing data from patient surveys to measure the effectiveness of the program. Results will most likely be released next year.

“We’re looking at from when we first brought in the patient navigators for Indigenous and Black/African-descent populations [about 18 months ago],” he said. “That’s when we reoriented things from being a crisis-care model to one that is proactive and longitudinal in nature.”

His hope is that the program will prove successful enough that it can be expanded to Fred Hutch’s other locations around the Seattle area and elsewhere in Washington state.

“Offering this service to patients no matter where they’re being cared for would be fantastic,” he said.

But that requires funding, of course.

“Right now, some of our navigators are funded through grants which is wonderful but nerve-wracking,” he said. “What if the grant doesn’t come through? We’ve all seen that happen. Making sure the navigators are funded through the Hutch’s operational budget would be a wonderful way to recognize how important and essential they are to the care team.”

Even without the survey data to back it up, Mendoza believes the patient navigation program has absolutely proven its value.

“This is one of the most unheralded programs at our center but it’s one of the most important,” he said. “They elevate the institutions. Some of the stories they tell us of their encounters with patients are simply breathtaking. And some have to do with small things that make a huge difference to the patient.”

For Schalau, the metastatic breast cancer patient that Devine helped with financial resources, those little things can mean everything.

“In the beginning, I was in shock,” she said. “I called Anne a few times to get advice and a pep talk and she was very helpful every time. She hooked me up with the right programs; she’d also tell you to ask for this, be aware of that. Those little hints were lifesaving. And she didn’t pity me. She never came off that way. She even put my name in for a Christmas giveaway and I got some grocery gift cards. That was so sweet; those touches were just fabulous.”

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