Rural Cancer Care

Rural residents with cancer tend to have later diagnoses and poorer outcomes. Researchers and oncologists are working to identify and remove the barriers they face.

BY MARK RAY

Sichon / turtix / Shutterstock.com

Moving home to Appalachia may have saved Jennifer Goggans' life. In 2006, after living in Seattle for 13 years, Goggans and her husband, Phil, returned to Paintsville, Kentucky, to raise their three children closer to family.

One of those children, Rebecca, has disabilities that prevent her from living independently. As Rebecca's full-time caregiver, Goggans did everything she could to keep herself healthy. That included eating right, getting plenty of exercise and keeping up with preventive care. Goggans had been back in Kentucky for four years when she found out about a University of Kentucky (UK) Markey Cancer Center study offering free annual ultrasound screenings for ovarian cancer in women 50 and older. Back in Seattle, she'd had an ovarian cyst removed, so she jumped at the chance to participate when she turned 50 in 2014. Although the cancer center is located in Lexington, some two hours away from Paintsville, Goggans received her free screenings just down the road in Prestonsburg.

"When they found the cyst on the other ovary, I just thought, 'They'll remove it, and it won't be cancer because I feel so good,'" Goggans says of the 2018 discovery. "Well, cancer can surprise you sometimes."

In fact, the 54-year-old had ovarian cancer and underwent a hysterectomy at UK Markey Cancer Center to remove the diseased organ. Her surgeon determined it was stage I cancer, meaning it hadn't spread beyond the ovary. Still, pathology from the tumor showed the cancer was likely to grow quickly, so Goggans returned to UK Markey Cancer Center for six rounds of chemotherapy. That meant multiple trips to Lexington, where she was usually accompanied by her husband, a close friend or her middle child, Susanna, who had just finished her first year at the University of Kentucky.

"I was fortunate it was summer and fall when I had my chemo," she says. "In the winter, it would be really nerve-wracking because you have to stay on your schedule, and if you have bad weather, the Mountain Parkway is not the best place to be."

The Challenge of Distance

Goggans, who completed treatment in October 2018, is one of an estimated 66.3 million Americans (20% of the population) who live in rural areas, which the Census Bureau considers areas with fewer

Nmaneer / Shutterstock.com

than 2,000 housing units or a population of less than 5,000. Rural residents in the U.S. are slightly more likely to develop some cancers—lung, colorectal and cervical cancers—than those who live in urban areas. Those who are diagnosed with certain cancer types are more likely to die of the disease, including melanoma (19% higher), lung cancer (38% higher) and cervical cancer (39% higher).

"There are certainly benefits to and strengths for folks living in tight-knit rural communities; in some ways, that can serve as a protective benefit," says Andrew Sussman, who directs the Community Outreach and Engagement Office at the University of New Mexico (UNM) Comprehensive Cancer Center in Albuquerque. "But when it does come to accessing these resources that they specifically need in a health care setting along this whole continuum—from prevention to screening to treatment to survivorship—all of the challenges of that daily access are made a little more difficult by distance, by higher rates of poverty, by the burden of the care that they need."

> "All of the challenges of that daily access are made a little more difficult by distance, by higher rates of poverty, by the burden of the care that they need."
>
> –Andrew Sussman, director of the Community Outreach and Engagement Office at the University of New Mexico Comprehensive Cancer Center

Room for Improvement

National Cancer Institute (NCI)-designated cancer centers excel at lab and clinical research that can lead to better approaches to cancer prevention, diagnosis and treatment. Most of the 72 NCI-designated cancer centers focus on community outreach and engagement and on addressing ongoing care inequities in their catchment areas, the geographic regions they serve. Those that include rural communities in their catchment areas work on closing gaps in care for those residents.

The Community Outreach and Engagement Office at UNM Comprehensive Cancer Center deploys a range of strategies to reach people in all 33 counties in one of the country's largest and most diverse states. "There's no one answer," Sussman says. "I think it's that mixture of high-touch and high-tech strategies that hopefully makes a difference."

The office has partnered with the Mexican consulate in Albuquerque to educate Mexican nationals and Mexican Americans about cancer prevention and screening information as part of the consulate's Ventanilla de Salud (Health Window) program. Oncologist Jessica Belmonte of UNM Comprehensive Cancer Center, who speaks English and Spanish, hosts regular Facebook Live presentations to promote cancer screenings and bust cancer myths. "We do it in Spanish; equity is a big passion of mine," she says.

To identify and eliminate barriers, the center relies on input from community partners who understand the unique needs of the populations they serve, whether it's Mexican Americans, members of 19 tribal nations in the state, or residents who don't belong to either group. "Part of the goal of our office is to make sure we're communicating back into the cancer center what are the priorities and needs to make sure that we're delivering care and providing materials and information in ways that are as optimal as possible for our patients," Sussman says.

One example shows how mundane yet profound barriers to care can be. "We just recently learned that our automated phone system was not working properly for other languages, and we were able to advocate for that infrastructure to be changed," says Angelica Solares, senior program manager at the UNM Comprehensive Cancer Center Community Outreach and Engagement Office.

The Ohio State University Comprehensive Cancer Center (OSUCCC) in Columbus serves patients from 32 Appalachian counties in the state, some of which have limited health care facilities. "There are five to seven counties that have no mammography facilities, that have no hospitals," says cancer researcher Electra Paskett at OSUCCC.

Several years ago, health officials from Gallia County, in Ohio's southeast corner, told Paskett that dozens of local women couldn't get follow-up care after Pap tests showed they had abnormal cells that could indicate cervical cancer. "We helped them write a grant to the Ohio Commission on Minority Health, and they were funded by that to purchase a colposcope," she says. "The colposcope went in the local health department, and then a local health provider donated his time to come in

Seven Reasons for Rural-Urban Disparities

In a July 2022 article in the *Journal of the National Cancer Institute*, researchers identified seven key factors that contribute to rural-urban disparities. They are:

Oncology Infrastructure

Oncology services are far more available in cities than in rural areas. According to the American Society of Clinical Oncology, just 3.1% of medical oncologists and hematologists practice in rural areas, even though 20% of Americans live there.

This disparity largely stems from economics since there aren't enough cancer patients in lightly populated areas to justify investments in facilities and personnel. That said, researchers say rural areas can support some services, including low-risk diagnostics and infusion therapy.

Health Insurance Coverage

Adults in rural areas are more likely than their urban counterparts to be uninsured or to be on Medicaid. Frequently, rural residents only seek Medicaid coverage after a cancer diagnosis, so they're often diagnosed late and thus have a poorer prognosis.

By contrast, cancer survival rates among children and adolescents don't vary between rural and urban areas. Researchers credit the widespread availability of health insurance coverage for younger people with closing the rural-urban gap.

Geographic Access to Care

Traveling several hours to get care is common, and that requires reliable transportation and often a driver. "As one primary care doctor in Appalachia said, there is no 'Ruber'—rural Uber," notes cancer researcher Electra Paskett at the Ohio State University Comprehensive Cancer Center in Columbus, who contributed to the *Journal of the National Cancer Institute* article. "Public transportation is just nonexistent, and there's no Uber or Lyft in those areas."

"And you're probably going to have to stay the night when you're done with your treatment or your appointments, so lodging becomes an issue," says oncologist Jessica Belmonte of the University of New Mexico Comprehensive Cancer Center in Albuquerque. "That's an incredible expense in terms of gas, lodging, time off of work."

Health Behaviors

Rural residents tend to fare worse on a wide range of behaviors that increase cancer risk. "Rural people tend to have higher risk factors. So they smoke more, they use alcohol more, they eat more unhealthy food. There is a ton of overlap between many of these things," says cancer researcher Nathan Vanderford, who directs the Appalachian Career Training and Oncology (ACTION) program at the University of Kentucky Markey Cancer Center.

Access to Primary Care and Non-oncology Specialists

Good cancer care starts with good primary care, but primary care is harder to access in rural areas than in cities. One study found there are 34% more primary care providers in urban areas than in rural areas (53.3 vs. 39.8 per 100,000 people).

"A lot of folks only go to urgent care or emergency care settings when there's a big problem like a really bad sprained ankle, but they may not be going for regular care," says Andrew Sussman, who directs the Community Outreach and Engagement Office at the University of New Mexico Comprehensive Cancer Center.

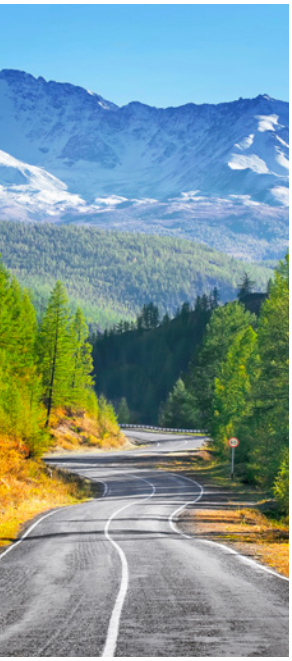
Access to Clinical Trials

Like other cancer care, clinical trials can seem out of reach to rural patients. "[Trials are] pretty rigid in terms of the scheduling of treatments and imaging or other diagnostics," says Belmonte. "When you explain the clinical trial to patients and they imagine traveling back and forth, it's a limiting factor."

That's unfortunate because clinical trial participation can lead to better outcomes, even for patients in the control arm. "We say clinical trials are the best treatment for anybody because you're never going to get less than the standard of care," says Paskett. "In addition to getting at least the standard of care, you are watched very, very carefully, so that's extremely important."

Information Needs and Health Literacy

Health literacy is markedly lower in rural areas, which leads to poorer health and higher mortality. One study found that rural residents were 33% more likely than city dwellers to have lower levels of health literacy.



Mindscape studio / Shutterstock.com

once a month." (Colposcopy helps determine whether abnormal cells are cancerous.)

Initiatives to advance equitable care often take time and planning. In Kentucky, UK Markey Cancer Center serves patients from 54 Appalachian counties in the state, but relatively few of its providers come from that region. "There are not enough people that are connected to those people and communities, and that leads to medical mistrust," says cancer researcher Nathan Vanderford, who directs the Appalachian Career Training and Oncology (ACTION) program at UK Markey Cancer Center.

In 2016, Vanderford founded the ACTION program to engage undergraduate students (and, later, high school students) from Appalachia in oncology education. Funded by NCI grants, the program brings students to Lexington to do research, shadow clinicians and explore oncology careers.

"We hope these students will become doctors, pharmacists, nurses, dentists or physician assistants—whatever the case might be—and go back and practice in their own communities or practice somewhere nearby, like Lexington, and help take care of patients from eastern Kentucky," Vanderford says.

To date, 34 participants in the program have gone to medical school. Ten have graduated and are in residency training. Two are on track to practice oncology.

> "There are not enough people that are connected to those people and communities, and that leads to medical mistrust."
>
> –Nathan Vanderford, director of the Appalachian Career Training and Oncology program at UK Markey Cancer Center

Joining them soon may be an ACTION participant who has seen cancer care up close. Susanna Goggans, the daughter of ovarian cancer survivor Jennifer Goggans, is now in her final year of medical school.

"The way my mom's doctor talked to her and our entire family had such a big impact on our entire experience," she says. "I want to be a doctor like that."

MARK RAY is a freelance writer based in Louisville, Kentucky.

Dawn Hudson / Shutterstock.com

Helping Survivors Thrive

According to researcher Kathleen Porter of the UVA Comprehensive Cancer Center in Charlottesville, Virginia, almost half of cancer survivors manage three or more chronic conditions. "We're getting better at detecting people early, and so we're able to have people come through on that other side cancer free, but they're still living with cardiovascular disease, diabetes, hypertension," says Porter, who works at a satellite office of the UVA Comprehensive Cancer Center in Christiansburg, more than two hours away from Charlottesville.

Unfortunately, lifestyle interventions for survivors are limited, even at the hospital in Charlottesville. "We don't have a comprehensive program to provide lifestyle interventions to our cancer survivors, and we're a very large cancer center," she says.

Improving posttreatment quality of life is the goal of weSurvive, an ongoing research study that Porter, research specialist Bréanna Foreman and other UVA Comprehensive Cancer Center faculty members are conducting. Funded by the American Cancer Society, the program groups Appalachian cancer survivors into cohorts of up to 20 people for 26-week periods. Members participate in eight group sessions via Zoom, where they learn strategies for improving their physical activity and nutrition, share their struggles and discuss their progress. They also receive three one-on-one coaching calls with Foreman to set and review goals, along with optional weekly motivational text messages. The program is open to adult cancer survivors living in or near Appalachian counties in Virginia, West Virginia, Tennessee, North Carolina and Kentucky.