On the Road Again: Searching for the Next Cancer Breakthrough at ASCO 2019

Why the head of the world's largest cancer organization braved dirt roads and crowded urban streets to reach impoverished cancer centers

June 13, 2019 By Bob Barnett

When I heard Monica M. Bertagnolli, MD, a professor of surgery at Harvard Medical School, address a massive auditorium full of oncologists and other cancer experts from around the world at McCormick Place in Chicago in early June, I was impressed by her journeys. In her year as president of the American Society of Clinical Oncology (ASCO), which was ending in a few days, she'd traveled to some of the most remote and most crowded communities in the United States.

She went to Puerto Rico, where, after Hurricane Maria hit, the staff at a San Juan cancer clinic made extra ice in their lab freezers so they could keep chemotherapy medicines cold.

She went to Appalachian counties in Ohio where cancer and cancer mortality rates far outpace the U.S. average. Towns lack jobs, grocery stores, cell phone access, transportation and access to doctors. To raise money to buy equipment to diagnose gynecologic cancers, one community came together over poker runs and bingo nights.

She went to Laredo, Texas, on the U.S.-Mexico border, where nearly a third of residents live in poverty and where, in 2002, there was one oncologist for a population of 300,000. Now there are three, and they are working hard to expand access to clinical trials for their patients.

She went to Kyle, South Dakota, where the members of the Oglala and Rosebud Sioux tribes have to travel 90 miles to get to the nearest oncology provider. Native American citizens have the worst outcomes after a cancer diagnosis of any racial or ethnic group in the United States. A local nonprofit, Walking Forward, offers culturally tailored patient navigation programs designed to bring American Indians into prevention and screening programs, including clinical trials.

Finally, she went to Queens Hospital Cancer Center, in Queens, New York, a borough

where 60% of the population belongs to a minority group and 108 languages are spoken. In this particular clinic, many people lack both health insurance and enough to eat. So the clinic opened a free food pantry. Some patients time their cancer treatment appointments to coincide with days

when the pantry is open so they can get treatment and food for their families at the same time.

Why did the ASCO president travel to these places? It wasn't just to shine a light on the health professionals who work so hard to bring care to these populations. Nor was it just to underline the disparities in cancer care brought on by poverty, lack of access to insurance, racial and other forms of discrimination and the often-crushing costs of cancer treatments. It was all that and something else: Expanding access to care—and learning from diverse populations—is the essential next step if the cancer community is going to advance science to find the best ways to treat everyone with cancer.

In an exclusive interview for Cancer Health, Bertagnolli explained why overcoming obstacles to expert care rivals clinical research in its impact—and can pave the way for future cures.

When we met, I told her that I'd been to many medical conferences, all with uplifting-sounding taglines that often don't mean much. ASCO's tagline this year—"Caring for every patient, learning from every patient"—was different. Its two parts relate to each other. Unless we find new ways to care for every patient who needs expert care and find new ways to share the knowledge gleaned from those diverse populations, we won't be able to develop the new knowledge needed to bring cancer care forward.

Caring for Every Patient: Saving Lives by Improving Access to Care

Why is access to care such a big issue now? Ironically, in part it's because we've made so much progress in new treatments. From the 2019 ASCO conference, for example, Cancer Health reported on clinical trials that demonstrated advances in treatments for cancers of the bladder, breast, colon, liver, lung and stomach as well as for the blood cancer multiple myeloma. There were reports on advances in treatments for children (many of whom are eligible for targeted therapies), for women with breast cancer who want to become pregnant, for the elderly and for people who are HIV positive. In recent years, better treatments, along with prevention and screening, have contributed to dramatic reductions in U.S. deaths from cancer. "The world has changed so much in the last decade," Bertagnolli said. "ASCO—and the medical field in general—has keyed in on new discoveries, new drugs, new therapies," she said. We have amazing drugs and therapies."

The problem? Many of these new treatments are prohibitively expensive. "We've always had haves and have-nots in society—it's not new—but the effects are now magnified by the spiraling costs of new drugs. Going forward, getting expert care to everyone who needs it may have an effect that is greater than clinical breakthroughs."

How big a difference could better access to expert care make? We don't know yet, but research that Bertagnolli highlighted in the plenary sessions this year suggests that the impact could be enormous. This year ASCO spotlighted three separate clinical studies that found that access to insurance coverage leads to better care and even a greater chance of survival. One showed that in states that expanded coverage to Medicaid as allowed under the Affordable Care Act (ACA), people

with advanced or metastatic cancers got treated much earlier, compared with states that didn't expand Medicaid; indeed, the improvement in care was so strong that it wiped out the racial disparity in access to care in these states. Another found that the ACA led to more women being diagnosed with ovarian cancer earlier, when outcomes are likely to be better. A third found that in people being treated for multiple myeloma, which is enormously expensive, those who had access to private insurance were more likely to survive than those on Medicaid or without insurance. "We know that getting a diagnosis sooner and being treated at an earlier stage increases survival," said Bertagnolli. "We're looking at the tip of an iceberg."

Expanding care to and research about everyone who needs it won't just help underserved groups fare better, as important as that is. It's also a key component to improving cancer care for everyone, Bertagnolli explained. That's where the second half of the tagline comes in.

Learning From Every Patient: The New Era of Big Data

"The very best data are randomized clinical trials, but only 3% of people with cancer participate in them," said Bertagnolli. As a result, she explained, these trials "vastly underrepresent minorities, rural populations, people without insurance and people over 65. The latter group, people over 65, represent 60% of people with cancer—but only 10% of the people in randomized clinical trials."

The result: We literally don't know how treatments will affect most people who are treated. That's why there is such emphasis these days on expanding the pool of people who enter clinical trials. Until recently, clinical trials excluded people who had survived other cancers, for example. But research has found that widening the pool of candidates has no negative effect on the validity of such trials. Doing so can nearly double the available candidates for such trials, according to a study presented at the conference. In another development at the conference, the Biden Cancer Initiative announced an oncology clinical trial information "commons" that brings together nine organizations, which will make it easier to find appropriate candidates for clinical trials.

It's not just clinical guidelines that keep people out of clinical trials, however. Socioeconomic barriers also keep many people with cancer from getting treated in academic centers where research is taking place. That's why clinics such as the one in Laredo that Bertagnolli visited are working so hard to help their populations enroll in clinical trials. Getting expert care to underserved communities includes improving access to clinical trials—and everyone benefits from expanding that pool.

In the near future, there may be new ways to harness Big Data to improve knowledge about how cancer treatments affect specific populations. That's the reasoning behind a large ASCO project called CancerLinQ. Most of the approximately 15 million Americans who are cancer survivors have data about their diagnoses and treatments stored in electronic medical records, or EMRs. The purpose of CancerLinQ is to find ways to share that data in ways that preserve patient privacy but help oncologists and other health professionals learn what worked for certain populations. For example, when a doctor is treating someone with a specific kind of cancer who is 75 years old,

that doctor could glean clinical information about how a particular treatment regimen affected people that age.

However, the medical community alone isn't going to bring expert care to everyone. Anyone who is affected by cancer can do their part—by participating in a clinical trial. People often have misconceptions about clinical trials—they think they'll be given a placebo rather than "real" medicine, for instance. But cancer trials are almost always different. One group gets the best current standard of care—what you'd get if you were getting excellent care but not participating in a trial. Another group gets that standard care plus a new therapeutic agent or protocol. No one gets less-than-professional care.

Advocating for improved access to clinical trials has to come not just from doctors but from patient advocates and everyone else affected by cancer. "Patients can be partners in tackling advocacy for health coverage," says Bertagnolli. Oncologists often hear their patients tell them that they want them to use their experience to help other patients. "The best way to do that, to help yourself and others, is to become part of a clinical trial. Get informed. You'll be making good decisions for yourself—and helping others."

"Life is strange and never perfect," said Bertagnolli. "But we can learn from experience and keep iterating and doing better. Tell your doctor that you want to be part of a clinical trial. We need to learn from every single patient's journey."

Read ASCO President Monica Bertognolli's speech.

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http://beta.docker.cancerhealth.com/blog/On-the-road-cancer-breakthrough-ASCO-2019