



The State of Cancer Care in America

A Perspective from The Council of Accountable Physician Practices and the American Cancer Society

EXECUTIVE SUMMARY

The Beau Biden Cancer Moonshot initiative by The National Cancer Institute sets forth an important goal to advance cancer treatments for all Americans by 2020. While cancer cures and effective treatments are critical, as a nation, we can do much to reduce the incidents of cancer and improve survival rates today. We need to ensure that all patients are protected from cancer risks; get the best chance for survival with access to coverage, care and early detection; and receive coordinated, evidence-based medical care by expert and consistently connected healthcare teams.

The Council of Accountable Physician Practices (CAPP), a coalition of the nation's leading multi-specialty medical groups and health systems, and the American Cancer Society (ACS) have come together to examine what can and should be done to close the gaps that now exist in cancer prevention, detection and care coordination.

Our contribution to the efforts to improve cancer care focuses on the patient experience in cancer care treatment and how organized systems of care can enhance that experience. While research for cures and treatments are underway, we believe that considerable progress toward these goals can be made by tackling prevention, improving the systems for early detection and fast treatment, and providing effective care coordination for patients with cancer.

This **State of Cancer Care in America** paper will address:

- The current situation regarding the effect of cancer on our nation; cancer disparities within the U.S. population; and the cost of cancer care
- The latest research into what patients and their doctors really want from the healthcare system
- The obstacles that exist today in preventing and detecting cancer in its early stages to improve survival rates
- The challenges in coordinating medical services for people with chronic diseases like cancer

It is our view that only a systems approach can close the gaps in care that result in poor outcomes, as well as bridge disparities caused by race, gender, and economics.

As a society, we must continue to act at both national and local levels to systematically curb the environmental causes of cancer, which include obesity and tobacco use.

On the care delivery side of the equation, a systems approach to identifying and treating cancer quickly and effectively requires that:

- Medical groups and health systems are well-integrated, organized and coordinated with each other and with payors
- Care decisions, treatment and innovations are led by physicians and clinicians
- Detection processes and strong communication and coordination between doctors and patients is incentivized appropriately, moving the payment of medical care from fee-for-service to payment-for-value models
- Health systems and physicians have strong robust health information technology to support good communication and coordination of information and services
- Data available through those robust technological improvements are used to measure and monitor the impact of cancer interventions and quickly move new cancer treatments into the healthcare system

Most importantly, without comprehensive health insurance that covers not only the cost of cancer once its detected, but also cancer prevention and screening measures that physicians prescribe, many Americans will not be able to access the care they need when they need it.

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THE CURRENT SITUATION

There Is Improvement in Survival Rates but Gaps and Disparities Persist

The United States has been waging war on cancer for the better part of a century. Developments in science and medicine are helping to win that war. That's borne out by the fact that the nationwide death rate for cancer in the U.S. has dropped 13 percent between 2004 and 2013.¹ Moreover, the Cancer Moonshot – the \$1.8 billion initiative for the National Cancer Institute to accelerate research over the next seven years – is expected to yield even more victories in the near-term.²

Nevertheless, one out of two American men and one out of three American women will develop cancer during their lifetimes.³ Economic and demographic disparities exist among U.S. cancer patients, creating a large gap in survival rates between geographies and demographic groups. Virtually all cancer patients are also burdened with paying a higher share of the cost for their care than they were just a few years ago. And, the alarming rates of obesity and chronic diseases are challenging the enormous progress that has been made in fighting the disease.

Take breast cancer as an example. Once it was all but a death sentence. But today, even a patient with the Stage III form of the disease has a 72 percent chance of surviving after five years.⁴ If treated in its earlier stages, the chances of survival approach 100 percent. Yet some residents of western Mississippi are more than five times more likely to die of breast cancer than those who live in other, more affluent parts of the country.⁵ There are similar disparities due to demographics and geography for prostate cancer. The relative survival rates for all prostate cancer patients is nearly 100 percent after five years and 95 percent after 15 years.⁶ But in several parts of the U.S., a prostate cancer patient is more than four times likelier to die of the disease than residents elsewhere.⁷

There are also gaps in cancer survival by race and gender that are often linked to lack of insurance or lack of a regular medical provider. According to the Centers for Disease Control & Prevention, the mortality rates for African-American males with cancer are 27 percent higher than non-Hispanic white males.⁸ The mortality rates among African-American women are nearly 20 percent higher than for white women.⁹ The chances of a black woman surviving ovarian and cervical cancer for five years has dropped from the 1970s. And incidences of cancer among American Indians and Alaskan natives have risen nearly 8 percent from 2000 – the only group in America where that number has grown in the 21st century.¹⁰

Demographic disparities in cancer treatment and prevention also persist. For example, Latinas over the age of 40 are nearly 10 percent less likely than white women to have undergone a recent mammogram, one of the keys to early detection of breast cancer.¹¹ And as a group, Latinos over the age of 50 are nearly 40 percent less likely to undergo a colonoscopy than whites, even though such testing is considered crucial for the early detection of colorectal cancer.¹²

Patients' Personal Care Costs Are Burdensome and Rising

Meanwhile, the personal financial costs for cancer patients are rising. The American Cancer Society Cancer Action Network determined that total out-of-pocket costs for cancer treatments in 2014 was \$4 billion.¹³ That does not even factor in costs connected to a patient's cancer diagnosis for non-clinical expenses, such as lodging near a treatment facility; child care; the cost of wigs and other cosmetic items to address the side effects of treatment; mental healthcare; and even more profound issues, such as job losses related to the illness or caring for a loved one who is ill.

Cancer patients who have health insurance also confront the possibility of having six-figure medical bills to pay off, particularly if they use out-of-network providers - a necessity for some cancer patients. One such patient after a diagnosis of pancreatic cancer had to go out-of-network to receive the expert care she needed in a timely manner.¹⁴ Even patients who stay in their provider network can experience up to \$80,000 in out-of-pocket costs.¹⁵ In addition to having to pay that debt, many cancer patients have far higher ongoing healthcare costs because of the testing and other medical maintenance required to keep them cancer free. Non-elderly colon cancer survivors may have costs approaching \$20,000 per year.¹⁶

Those huge costs also appear to have a disproportionate impact on people of color. According to the CDC, even after the Affordable Care Act has helped millions of uninsured to gain coverage, African-Americans were nearly 60 percent more likely than whites to put off healthcare services due to their costs, suggesting that preventive and follow-up care are being sacrificed.¹⁷

Given that one in three Americans will get some form of cancer, the notion of reducing or eliminating insurance coverage is extremely troubling. Studies have shown that nonelderly cancer survivors are particularly vulnerable to changes in prescription drug use for financial reasons.¹⁸ Research conducted in Massachusetts and after the passage of the Affordable Care act indicate that expansion of health insurance coverage also increases access and use of preventive services. Impending threats to coverage could reverse what appears to be a positive shift to increasing prevention and early detection.^{19,20}

Both Patients and Providers Are Not Getting What They Need from the System

Despite the belief that a trusted doctor-patient relationship is viewed as being the important component of good care, there are significant communication gaps between doctors and their patients. In a 2016 CAPP survey, physicians stated that they regularly counsel their patients about

how to prevent illness, however, patients said they were not hearing their physicians recommend lifestyle changes that would help prevent the onset of diseases like cancer, such as increasing physical activity.²¹

The same goes for encouraging preventive screenings. Eighty-nine percent of doctors said they recommend them, while only 14 percent of patients said they had received those reminders. (In recent focus groups—see sidebar in this paper—patients also report that this advice sometimes makes them feel “managed” and is not always well received or acted upon.)

That 2016 CAPP research also found that people with chronic illnesses are only slightly more likely to have coordinated care than individuals who have no chronic illnesses,²² even though both patients and doctors seem to understand the value of coordinated care, and many patients would expect it from their providers. (Coordinated care was described as team-based care, where providers have current and complete medical information, work and communicate together about a patient’s care, and follow up with patients.)

Research from the Patient Advocate Foundation also demonstrated a significant gap in the preferences of cancer patients and their actual experience. For example, 97 percent said it was important to them to avoid complications that would diminish quality of life, but only 70 percent experienced this preference. Being able to spend more time with family was important to 87 percent of patients, but only 65 percent realized that expectation. One in four wished they had had help or advice to reduce stress and anxiety, and 37 percent would have liked assistance or advice on how to control fatigue. Almost one-third would have appreciated help in figuring out how to pay for care.

Finally, when comparing responses of African-American patients with Caucasian patients, almost three times as many African-American respondents would have liked to have had resources such as advice on how to stay fit, complimentary parking, help with diet improvement, paying for care and pain management. These differences indicate significant gaps in the availability of these resources to African-American versus Caucasian patients.²³

How do we create the desired healthcare experience for the millions of Americans who may discover they have cancer and will need to undergo treatment?

A significant part of the solution is to improve the healthcare system to do a better job in helping patients prevent cancer, detect cancers early and make the treatment of cancer easier, more convenient and efficient.

NEW RESEARCH ON WHAT PATIENTS AND PROVIDERS WANT FROM THE SYSTEM

How Do Patients and Doctors Define “Good” Healthcare?

The Council of Accountable Physician Practices recently conducted new focus group research with separate groups of patients and physicians, who were asked what they considered to be the most important attributes of healthcare delivery. They were instructed to choose and rank 22 attributes of care delivery, which were then clustered into seven categories: the doctor-patient relationship, evidence-based medicine, coordinated care, prevention services, facilities, access, and technology. While none of the 22 attributes in those seven clusters were deemed as totally unimportant, some were of higher value than others.

The groups revealed that the most important attributes of quality care for both patients and physicians are: a strong doctor-patient relationship, evidence-based medicine, and coordinated care. While the importance of personal doctor-patient relationship was not surprising, what was interesting is that both were in accord that treatment should be based on evidence and shared-decision making.

Patient:

“I have some odd conditions and I always appreciate that [the doctor] is on top of the possibilities and he knows what tests to do and what it could be. He’s like a detective. He must be up to date in order to do that. That is very important to me.”

*“Nowadays, things change so quickly. **New surgeries, new technologies, new medications.** You can love your doctor to death and you could have him for 25 years, but if he’s still working with the technology from 25 years ago, it’s not best for you.”*

Physician:

“It’s got to be evidence-based. There are people out there who know disease X is treated with drug Y. You’ve got to look at other people’s practices as well as your own...”

And the concept of care coordination was easily grasped by patients and valued by doctors. Care coordination was described as team-based care, where providers have current and complete medical information, work and communicate together about a patient’s care, and follow up with patients. Both patients and doctors believe in the importance of these attributes:

Patient:

"If you're really bad off, if you have severe diabetes, cancer, whatever it is...you [want to] have those team meetings. Then you have one nurse overlooking everything."

Patient:

"My husband died from lung cancer. There were things that I would look up [myself] and call the doctor's office [about it] and they'd say, 'Oh sure, we can do that.' Why in the blue bloody blazes why aren't you offering that? . . . I do want my doctors up to date on stuff. I will always do the research, but I don't always want to have to."

Patient:

"My mother had cancer. She had to see a urologist, she had to see a nephrologist, she had a number of doctors to see at one time. They all should coordinate with each other [about] her care."

Physician:

"Medicine is a lot more of a team approach where you're trying to . . . coordinate the whole team. Some patients just go to specialist. Some patients just go to primary. The vast majority go to both and you have to work with them to try to get them the best care."

Physician:

"We can have patients who are seen in an emergency department and are brought back from their overdose... and then they are back at their primary care doctor receiving the same prescription that landed them in the hospital."

Doctors ranked technology, including electronic medical records and online tools for patient engagement, as the least important cluster of healthcare attributes. Patients felt technology was important, but not high on the list.

CURRENT CHALLENGES WITH CANCER PREVENTION AND EARLY DETECTION

Cancer Often a Result of Lifestyle Factors and Obesity

Lifestyle factors and the obesity epidemic are obstacles to effective cancer prevention. The World Cancer Research Fund International estimates that about 21 percent of all cancer cases diagnosed in the United States are due to a combination of excess weight, poor nutrition, physical inactivity, tobacco use and excess alcohol consumption, and therefore could be prevented.²⁴

For some types of cancer, such as esophageal adenocarcinomas, 37 percent are believed to be preventable among American men and 30 percent among women. Recent data indicates that in 2017 about 190,500 cancer deaths in the U.S. will be caused by cigarette smoking alone.²⁵

Moreover, the rate of physical activity among individual Americans lags significantly behind what would be considered acceptable to maintain a healthy lifestyle. Only about one in five adults get the recommended amount of aerobic and muscle strengthening physical activity. Less than three in 10 high school students get at least 60 minutes of physical activity in a day.²⁶

The American diet is also a culprit. The typical diet is comprised of foods high in fat, refined carbohydrates, and added sugar, which add little nutritional value, contribute to weight gain and increased concentrations of factors that promote cancer.²⁷

The overall rates of preventable cancers in the U.S. are significantly higher than in the United Kingdom, Brazil or China.

Cancer Screenings and Vaccinations Lag

Although more providers and health plans have been promoting preventive cancer screenings, large numbers of Americans still do not undergo them in a consistent and timely fashion. According to the CDC, nearly a third of women still do not undergo regular pap smears.²⁸ More than a quarter of insured women over the age of 40 have not had a mammogram in the past two years. That figure rises to more than 60 percent among women who lack insurance.²⁹

The human papillomavirus (HPV) can cause six types of cancer, yet while HPV vaccinations are



Daria's Story

Many health systems in the U.S. strive to proactively screen, test and support patients who need a team-based approach to care and coordination of services.

Daria's story is an example of how closing gaps in the healthcare system can help patients get the preventive screenings they need, as well as improve overall outcomes. The creation of the safety net of information, proactive intervention, and proactive treatment is an example of true care coordination for better outcomes.

Daria's multi-specialty medical group, The Southern California Permanente Medical Group, has set an ambitious and specific goal to cut colon cancer mortality rates in half within 10 years. The initiative began four years ago with an analysis on the causes of mortality for colon cancer patients and the relationship to mortality of each phase of diagnosis and treatment. Researchers found that improvement opportunities existed at multiple stages of care, including screening, evaluation of symptoms, timeliness of care, use of adjuvant chemotherapy, and surgical oncology practices. By focusing on these areas, Southern California Permanente Medical Group has in just three years reduced the mortality rate of colon cancer patients by 17%. By improving the system of care, lives are being saved and improved.

known to reduce the HPV-associated cancers and are medically recommended, the rates of HPV vaccination among adolescents lag compared to other recommended vaccines.³⁰

Avoiding regular screenings tend to compound cancer cases when they do arise. A recent study by Kaiser Permanente concluded that delaying a colonoscopy after a positive fecal test not only greatly increased the risk of a positive cancer diagnosis, but also the likelihood that the cancer will be in an advanced state.³¹

While people may be avoiding screenings and doctors may not always be providing them, recent studies have shown that, with the coverage provided by the Affordable Care Act, early cancer detection grew.

CURRENT CHALLENGES WITH CARE COORDINATION

U.S. Coordination of Care Worst Among Industrialized Nations

Care coordination is considered by many healthcare experts to be a key to successfully treating a cancer patient and bringing the disease into remission. Yet obstacles to properly coordinate care can begin almost as soon as a patient receives an abnormal screening. The follow-up process can be overly complex for a patient. Moreover, their providers may not be able to assign them to a care “navigator” or other individuals responsible for shepherding them through the care process. Lack of care coordination can lead to medical errors and repeated tests, driving up costs and driving down positive outcomes.

This situation for American patients is borne out by recent research data by the Commonwealth Fund concluding the U.S. has the worst levels of coordinated care among 11 wealthy countries.³² About 40 percent of American patients report at least one gap in the care they receive, and about 10 percent have three gaps or more – the highest level by far of any of the reporting countries. Previous CAPP research shows that even patients who suffer from chronic illness say their care is only slightly more likely to be coordinated than those without such conditions.³³ That’s despite the fact many patients now know what coordinated care means and understand its value.

The Dominant Fee-for-Service Payment System Does Not Support Coordinated Care

Additionally, the often-fragmented fee-for-service payment system of healthcare in the U.S. works against systematizing coordinated care. Many detection and preventive measures that doctors could take are not paid for in fee-for-service contracts with insurers. Patient navigation services are often not covered. There is no real incentive for providers to engage in shared-decision making conversations about treatment. Payment for volume versus payment for value encourages the use of services without a holistic view of their impact on the clinical outcome.



Hunter's Story

Hunter's story illustrates how coordinated care not only contributed to her positive outcome, but dealt safely with an unexpected development.

The care system that Hunter and her mother referred to as "family" is Pennsylvania's Geisinger Health System. Several system enhancements improve care for pediatric cancer patients at Geisinger. First, physicians can communicate by sharing the system's comprehensive electronic health record and frequent phone conversations. Being in an integrated system allows these doctors to ask the right questions to minimize inappropriate treatment or over-treatment. This close communication and collaboration played a big part in the detection of symptoms of Hunter's brain tumor that delayed her first colon cancer surgery and refocused the team on fighting this additional major health threat.

Geisinger stresses rapid treatment for pediatric patients, and treatment that is compassionate, considerate of the psychological consequences of this diagnosis for patients and their caregivers. Because many patients travel long distances from rural areas, Geisinger allows patients to receive testing at satellite centers statewide, since physicians can see the results in their EMR. Patients and families can also speak with physicians remotely. As many appointments as possible are scheduled on the same day to minimize the stress of travel. This type of integrated and coordinated care makes a challenging situation much easier for patients and families, and connects the healthcare team with the information they need to deliver coordinated, evidence-based patient care.

Lack of Meaningful Connectivity Between Providers Affects Care Delivery

The fragmentation of care in the current system is compounded by the lack of technology to connect team members and patients. The inability to use the electronic medical record (EMR) for clinical care across provider organizations means that a cancer patient's often numerous providers cannot communicate and have access to information in real time, leading to delays in care and miscommunications.

Consequently, patients are often left adrift in a complex system and subject to sometimes extraordinary financial burdens at a time when they are vulnerable and need to focus their energy on getting well.

RECOMMENDATIONS

Based on these realities, the Council of Accountable Physician Practices and the American Cancer Society present the following recommendations:

Prevention and Early Detection

- Ensure that all Americans have access to adequate coverage and understand the value of preventive measures and screenings. This should be a common goal for everyone concerned about the impact of cancer on Americans, not only healthcare providers.
- Continue to push for more preventive screenings. The ACS is moving to get 80% of Americans over the age of 50 to be screened for colorectal cancer by 2018. The ACS's HPV VACs (Vaccinate Adolescents against Cancers) Project seeks to increase HPV vaccination rates for adolescents across the nation.
- Use the electronic medical record (EMR) as a clinical tool to manage care and to enable the entire care team to be aware of preventive screenings or vaccinations that a patient needs. Specialists as well as primary care physicians should have access to the patient's entire medical record so that they will know when screenings or vaccinations are due and can remind patients. Create a culture throughout the care team where everyone takes responsibility for ensuring that patients get these preventive screenings.
- Ensure that providers are reimbursed adequately for preventive screenings and vaccinations.
- Use big data to better manage populations of people who might be likely to develop cancer. Identify at-risk populations and concentrate resources on educating them and ensuring they undergo crucial preventive testing. At the same time, use technology to deliver non-intrusive but culturally sensitive prods toward better preventive care (i.e., appointment/screening reminders delivered by phone in the appropriate language for each patient).
- Empower communities to fight cancer by addressing health determinants (i.e., environment, access to healthy food) before they lead to a cancer diagnosis. Promote better nutritional intake, more physical activity (along with creating more public "green spaces" for recreational activity) and generally healthier lifestyles. Reduce the prevalence of smoking and the use of other tobacco products.

Care Coordination

- Care coordination and navigation should be available for all cancer patients and their caregivers. It should begin as soon as a patient receives an abnormal screening. Care coordination should continue through the treatment process and into follow-up care when patients are in remission.

- Navigation should be tailored to the patient's level of need using simple measures such as patient activation level, health literacy level, access to transportation, etc.
- Cancer care teams, labs and imaging services should be better integrated with technology. Such teams should have universal access to electronic medical records that allow more holistic and faster clinical decision-making while eliminating duplication of efforts.
- Care plans for cancer patients should be designed with an eye to being convenient to patients and families, with such options as remote connections to reduce drive and wait times, multiple appointments scheduled on a single day, and rapid communication on test results and follow-up treatment.
- Care coordination is enhanced when patients are engaged and activated in their healthcare. Taking actions to ensure patients have the information they need, when they need it and engaging them in decisions about their care and the care process can help ensure coordinated care efforts produce positive outcomes.
- Cost burdens for patients must be reduced to ensure they pursue a consistent course of care and are not discouraged from making and keeping appointments, which can disrupt care coordination.

CONCLUSIONS

Across the nation, patients, families, and their dedicated care teams are fighting valiantly to defeat cancer. While the Cancer Moonshot focuses on fast-tracking research to find cures and new medications, we have an ongoing obligation to improve the healthcare that cancer patients can receive today, so that outcomes are improved and survivorship is increased.

CAPP and ACS' aim for 2017 and beyond is to improve preventive cancer screenings, give all patients access to integrated, coordinated systems of care, close disparities among minority groups and reduce the cost of treatments for cancer patients.

Around prevention, the movement toward creating healthier environments, helping people make healthier lifestyle choices to reduce cancer risk, especially around tobacco use, is critically important to influence the incidence of cancer for years to come.

At the policy level, we must preserve access to care and continue the impetus to payment for value versus payment for volume. Healthcare policymakers must preserve coverage for pre-existing conditions and affordable coverage options for people in the individual market. Any overhaul of the Affordable Care Act should preserve essential healthcare benefits, including all those related to preventive care and early detection of cancer. There is significant evidence to show that out-of-pocket expenses for the nonelderly affect their healthcare decisions.³⁴ No patient with cancer, or any disease, should have to face the challenge of treatment and recovery without access to affordable healthcare.

As a nation, we must be committed to additional reforms in our healthcare system that will reward outcomes, provide electronic connectivity for all healthcare providers, and help relieve cancer patients of the stress of coordinating care.

All healthcare delivery systems should adopt the pillars of care coordination, technology, prevention, and physician leadership that will close the gaps in cancer care and prevention. As these gaps are eliminated, so too is the likelihood of medical errors, delays in care, and missed opportunities for screenings and early detection. As all patients get the same level of proactive, coordinated care, the disparities that now exist in geographies, economic groups, and racial and ethnic populations will even out and eventually disappear.

The technology that links care providers and patients to expedite care and communication must be enhanced. Expanding digital healthcare communication can lead to broader acceptance and appreciation of its benefits.

And, based on the understanding that patients now have about the importance of care coordination, providers should strive to educate patients on the value of team care needed to support individual doctors and the importance of doctors having the integrated, technology-enabled system to support them.

Transforming healthcare delivery—and cancer care—in this fashion will result in better clinical decisions and proactive treatment, reduce medical errors, and improve the patient experience. Following these recommendations can also provide the connections that will significantly improve prevention and reduce disparities. Integrated, comprehensive and coordinated systems of care are the key to closing the gaps in cancer care that exist today.

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