



Ensuring Access to High-quality Cancer Care in California

Executive Summary

Expansion of patient access to health care coverage under the Affordable Care Act (ACA) has been, in many respects, a tremendous benefit to cancer patients. However, improvements are needed to ensure that the 'health care ecosystem' in California works for all cancer patients.

California adopted managed care earlier than most states, and we have evolved to leverage a "delegated model." Medical groups have taken on a gatekeeper role. They are all anticipating a more physician-driven approach to care, with more care coordination and physician-to-physician communication in order to control costs. The delegated

medical groups are at financial risk for hospital care, utilization and referrals to out-of-network specialty care. In the case of cancer care, however, the system may lead to inadequate access to the required expertise and experience and result in higher, not lower costs.

The health care system's ability to control the cost of oncology care while improving health outcomes must be a shared goal of the public and private sectors. Covered health care systems and narrow networks may be effective in managing the costs, but in the case of cancer patients, they may not enable patient access to the best available care.

Ultimately, what cancer patients value most are outcomes, quality of life and survival, and the ability to trust that they are receiving the appropriate care by a specialist with experience in treating their type of cancer.

Cancer Is Different

Cancer is now recognized not as one condition, but as multiple conditions. With the emergence of genomic sequencing technology, cancer may soon be viewed as potentially hundreds of conditions. In the near future, it is likely that cancer diagnoses will be characterized as much by distinct genetic mutations as by the site of origin. Large data sets hold promise for speeding scientific progress and providing greater insight into the value of individual options.

Hospitals and physician groups have widely varying levels of expertise for various types of cancer. Hospital performance ratings do not reflect the levels of expertise for all the varying types of cancers. As a result, exclusions of hospitals with cancer expertise in certain areas can strain or impede care for many cancer patients with complex cancers best treated by oncologists who have experience in treating patients with that type of cancer. Ultimately, what cancer patients value most are outcomes, quality of life and survival, and the ability to trust that they are receiving the appropriate care by a specialist with experience in treating their type of cancer.

Narrow networks may limit access to the expertise that is necessary to deliver the best treatment and outcome for a cancer patient.

Narrow Networks

Consumers do not plan to receive a cancer diagnosis when selecting a health plan. The purchase of health care coverage is an infrequent purchase, and consumers do not have full knowledge of the financial implications associated with selecting a health plan that does not adequately cover the significant costs associated with illnesses such as cancer. Nor are they aware of the quality ratings of the providers covered under their plan.

Most consumers select their health plans largely on the basis of premium affordability and whether their primary care physician is in the network. They do not usually anticipate the cost sharing burdens of high-deductible plans should they experience a serious illness. Plans that limit access to a narrow network of providers exacerbate the problem because out-of-network care is unaffordable for most patients or not covered by the plan. Out-of-network benefits are not highlighted due to costs.

Payers use narrow networks to reduce or in some cases eliminate access to hospitals that are considered expensive. Many insurers design health plans with a restricted choice of providers, allowing them to offer the plan at a relatively low premium. Such limited network plans are common in Covered California, the health benefit exchange created under the ACA, as Covered California has driven costs down to attract lower-income consumers. But, in many cases, these narrow networks do not include access to a National Cancer Institute-designated comprehensive cancer center (CCC) such as City of Hope. As a result, a narrow network creates barriers for cancer patients in obtaining specialized, potentially lifesaving care in a timely manner.¹

Some of the barriers to CCCs also occur at the HMO medical group level. The delegated model was designed to eliminate waterfall care, not to eliminate resources from specialty care. Unfortunately, it has resulted in diminished investment in — and access to — specialty care for those patients who need it most. Market consolidation is contributing to access issues because physician affiliations are impacting referral patterns; doctors have incentives to refer within their

own health system, not necessarily to the most qualified specialist, which can be critical for a patient with a rare or complex cancer diagnosis. Narrow networks may very well work for patients with back pain or gallstones, but not for cancer patients.

Expertise Matters

In cancer care, expertise matters. Next-generation genome sequencing, adoptive immunotherapy, gene therapy and precision medicine are moving us away from the historic “one-size-fits-all” approach to treating diseases. Narrow networks assume that for each cancer patient, the needed expertise is ubiquitous.

This may be the case for some common early-stage cancers. But, for other rare or complex cancers, such as acute leukemia or other blood cancers that require highly specialized interventions, a limited network may deny a patient access to the care or expertise available at a CCC. Many of these patients lose their lives or live a shorter lifetime of chronic illness, pain and suffering.² This point is reinforced in two recently published papers: “Value, Access, and the Cost of Cancer Care Delivery at Academic Cancer Centers;” and “Disparities in Stage at Diagnosis, Survival, and Quality of Cancer Care in California by Source of Health Insurance.”³

Access to Research Is Good for Patients

The need for access to the proper expertise is heightened by the reality that cancer is an evolving field, one that requires ongoing research and access to the most recent data and technology. For those concerned with cost containment, the concept of clinical research can be scary (or even antithetical), and assumed, often correctly, to add expense. But, that is not always the case.

Many times, the best treatment choice for a cancer patient is a clinical trial that is offered in limited locations. As a society, we need to decide what value we place on research. Already we are seeing a shortage of patients for clinical trials; if these shortages persist, they may curtail the ability of researchers to advance important



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treatment breakthroughs. When it comes to rare and complex cancers, patients need and deserve immediate access to providers who have the track record and expertise to treat and cure diseases. The consequences of limited or delayed access are significant, leading to misdiagnoses that can often mean unnecessary exposure to toxic chemotherapy agents, suffering or avoidable death.

Adverse Selection

Narrow networks exist today to curb the cost of health care and avoid adverse selection. One reason insurers exclude some institutions — including CCCs and academic centers — from their networks is to offer a health plan that is affordable, especially to lower-income consumers. Another reason is to avoid disproportionately attracting the chronically ill or those with preconditions, including cancer diagnoses. Health plans or medical groups that include specialty hospitals attract patients already diagnosed with chronic conditions, creating adverse selection.

In today's environment, this places undue financial pressure on any risk-bearing enterprise — such as a health plan or medical group — that chooses to include high-quality, nationally renowned cancer institutions in its network. But, if all plans in the market include the institution, then the risk of adverse selection would be mitigated. It is when only one or a few include the institution, and the others do not, that the well-intentioned health plan or medical group may find themselves disadvantaged relative to their competitors.

This concern over adverse selection has the potential to create a “race to the bottom,” where health plans compete to have the least attractive services for critical illness, and focus more on wellness or general care. As the population ages, this will become an even greater concern.

Cost and Outcomes

Cancer care is expensive, but mistreating patients is more expensive, particularly in human costs. When patients with rare or complex cancers have access to care at a CCC, they often experience better outcomes at lower costs.⁴ Research has documented

significant differences in outcomes, including survival, if a patient is seen at a community hospital versus an academic center, or versus a National Cancer Institute-designated CCC.^{5,6}

While many cancer patients can, in fact, be treated conveniently — and cost effectively — in community settings, those with complex and rare cancers require access to clinical and specialized care often available only through centers of excellence such as NCI-designated CCCs.

Leading NCI centers and other academic medical centers are also at the forefront of research and scientific innovation, which speeds the delivery of novel and next-generation therapies to patients in most need and potentially leads to new therapies for future generations of patients.

Patient Choice

Patient choice should be taken into account in the selection of a treatment center, as the physician-patient relationship and convenient access to care are critical for patients' survival and quality of life. When patients and their families are dealing with the often debilitating symptoms of the disease and side effects of its treatment, they need social, financial and psychological support. Easy access for the family or caregiver is critical.⁷

Convenience plays a critical role for any chronically ill patient, but particularly when one is ill with cancer. In the middle of treatment and weakened by both the

condition and the interventions, choice takes on greater importance. Patients with cancer typically value ease of access to an oncology clinic. Patients will also frequently value how their psychological and social needs and those of their family are being met. Often, this level of comprehensive, patient-centered care is available only at a CCC.⁸

Summary

The ACA has further exposed the challenges we face in improving cancer care while making it affordable and accessible. While the act has had favorable impact on access to coverage, there is risk to the quality and integrity of the delivery of care for patients with highly specialized conditions like cancer. We believe that incentives that deny patients access to the expertise required for their condition should be removed. Instead, incentives should exist for physicians to refer cancer patients to NCI-designated comprehensive cancer centers, when doing so will improve patients' choices of receiving the most advanced care available, which often means enrollment in a clinical trial.

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