SPECIAL SERIES: ECONOMIC ISSUES IN CANCER CARE

review articles

Insurance Networks and Access to Affordable Cancer Care

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INTRODUCTION

Payment for cancer care in the United States occurs in the context of a complex system of private and public health insurance coverage. As of 2017, approximately one half of Americans had employer-sponsored private health insurance, 7% were insured under private individual health plans, 21% under Medicaid, and 14% under Medicare.[1] Another 9% of patients were uninsured, with substantial geographic variation, ranging from 3% in Massachusetts to 17% in Texas.[1]

These diverse health care payors are under substantial pressure to control spending on health care. The health care industry now constitutes approximately 18% of gross domestic product[2] in the United States, representing $3.5 trillion in expenditures in 2017.[3] Health care spending per capita in the United States is approximately twice as high as in comparable high-income countries.[4] The cost of cancer care, which has been projected to reach up to $173 billion annually by 2020 (approximately 5% of total health costs),[5] represents an important component of health spending.

Requiring that patients seek care from contracted providers within a network of providers offering negotiated rates is one strategy used by insurers to control costs.[6-8] This practice may be one of few available in the context of an Affordable Care Act (ACA) requirement that qualified health plans be issued and priced equivalently for all individuals without regard to preexisting medical conditions.[9] However, concerns have been raised about the narrow provider networks that can result from this strategy. Narrow networks offer a limited selection of providers in a given geographic area, sometimes defined as 25% or less of all area providers.[10] Up to one half of the plans available on the marketplaces established by the ACA and more than one third of Medicare Advantage plans offer narrow networks.[9,11] Narrow provider networks may in some cases promote coordinated care delivery, particularly if they include providers who are affiliated with well-integrated health systems[12,13]; however, even well-integrated health systems may not consistently outperform more traditional practice arrangements with respect to either care quality[14,15] or cost.[16]

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Since access to tertiary and specialty care is not an explicit component of the definition of essential health benefits within qualified health plans under the ACA,[17] narrow provider networks could potentially discourage enrollment and limit access for patients who are in need of complex specialty care, including those with cancer.[14] The objective of this report was to review the structure of provider networks, the regulations governing them, and the implications for patients with cancer who must navigate them.

PROVIDER NETWORK STRUCTURES

Payors commonly offer access to health care providers in the context of health maintenance organizations (HMOs) or preferred provider organizations (PPOs).[18] Patients who are enrolled in an HMO are incentivized to obtain all covered care, other than emergency care, from an in-network provider. Such providers may either be independent practitioners or employed by a managed care plan.[19] Patients who seek care outside the HMO's network of providers may be responsible for the entirety of the costs of this out-of-network care. Patients with HMO plans generally require referrals from their primary care physicians to see specialists, which confers a gatekeeping role on primary care providers. HMOs constitute a common structure across private employer-sponsored plans, representing 16% of covered workers in 2018.[20] Currently, approximately one third of Medicare beneficiaries are enrolled in private Medicare Advantage plans, and 62% of Medicare Advantage enrollees had an HMO plan in 2019.[21] Up to 82% of Medicaid enrollees are enrolled in state-managed care organizations,[22] which generally use an HMO or similar primary care case management model.[23,24]

Plans with PPO networks generally charge higher premiums than those with HMOs but provide enrollees with greater flexibility with respect to providers. Within a PPO, patients may seek care from both in-network (preferred) and out-of-network (nonpreferred) providers, but they typically face additional out-of-pocket costs if they seek care out of network.[25] In particular, when patients with PPO plans seek care out of network, this care does not necessarily count toward the statutory annual out-of-pocket maximums for private health plans established by the ACA. These

maximums—$7,900 per individual and $15,800 per family in 2019—provide some protection against catastrophic costs incurred through treatment of unexpected serious illness. PPO plans may choose to offer out-of-pocket maximum limits for out-of-network care, but an increasing proportion do not,[26] which potentially leaves patients exposed to large out-of-pocket expenses for out-of-network care, particularly if providers engage in balance billing—charging patients for any portion of fees not covered by the health plan.

In 2018, 49% of covered workers in employer-sponsored plans were enrolled in PPOs.[20] Other provider network structures include point-of-service plans, which are similar to PPOs but may require referrals for specialist visits, and exclusive provider organizations, which are similar to HMOs in that out-of-network care may not be covered but which may not require referrals for specialist visits.[25]

Over the last decade, there has been a substantial increase in the prevalence of high-deductible health plans (HDHPs).[27] As of 2019, these constitute any insurance plan that requires that individuals pay at least $1,350 for an individual or $2,700 for a family before the plan begins to provide financial coverage.[28,29] HDHPs may be combined with tax-advantaged health savings accounts; the combination of an HDHP and a health savings account is often termed a consumer-directed health plan.[30] The goal of HDHPs is to encourage cost-conscious consumer behavior in health care. Nevertheless, plans with this payment structure have been associated with significant financial burdens for patients.[27] HDHPs are not synonymous with any particular provider network structure.

REGULATIONS GOVERNING PROVIDER NETWORKS

Historically, regulation of private health insurance plans was largely a matter of state law. Some states required only that provider networks be qualitatively "adequate," without defining "adequate." Others defined quantitative standards with respect to distance to providers, patient-to-provider ratios, and wait times for services.[9] Similarly, Medicaid managed care programs were regulated at the state level, and Medicaid provider network standards were highly variable.[31] The national Centers for Medicare & Medicaid Services (CMS) strengthened its oversight of state Medicaid provider networks in 2016, requiring that states define standards with respect to travel time and distance to care[32]; however, alterations to these requirements, including returning more oversight to states, are now under consideration.[33] CMS also regulates Medicare Advantage network adequacy, defining minimum standards with respect to the number of in-network providers, ratios of providers to patients, and travel time and distance.[34]

For private health plans, the ACA codified federal requirements that qualified plans offer networks that ensure sufficient choice of providers to facilitate access without unreasonable delays, as well as provide publicly available provider directories.[17,35,36] At the federal level, there are no quantitative definitions of sufficient choice or unreasonable delay. For patients with cancer—and particularly for those with rare or complex cases—these regulations are particularly salient; ready access to specialists with relevant expertise is not necessarily guaranteed. States retain an important role in regulating private plan networks, and requirements around provider-to-enrollee ratios, frequency of network directory updates, and travel time and distance still vary by state.[35]

Simultaneously, short-term health plans are becoming more prominent. Historically, these plans have offered coverage for, at most, 3 months at a time. They do not necessarily cover the essential health benefits required by the ACA, such as prescription drugs or maternity and mental health care,[17] and as such do not fulfill the ACA's individual mandate for coverage to avoid a tax penalty. Unlike qualified health plans, short-term plans can exclude coverage of preexisting conditions and set premiums on the basis of on a patient's medical history. Given these restrictions, short-term plans frequently have lower premiums than qualified health plans.[37] However, short-term plans are not subject to the ACA's network adequacy requirements. Some may not even offer specific provider networks at all. Among those plans without specific networks, coverage for services can be variable, leading to high out-of-pocket costs for patients.[38] Patients who are diagnosed with a serious illness while insured by a short-term plan may therefore confront major challenges in accessing necessary care. Recent federal policy shifts, including eliminating the tax penalty for foregoing qualified health plan coverage and allowing short-term plans to be purchased for up to 12 months,[39] seem to be intended to encourage enrollment in these plans. The Congressional Budget Office has estimated that up to 5 million more individuals will enroll in this type of plan over the next decade as a result of these policy changes, approximately 80% of whom would otherwise have enrolled in conventional plans.[40]

Given the increasing prevalence of narrow networks and short-term plans, patients increasingly may encounter out-of-network providers without realizing that those providers are not in network. This issue of resulting surprise billing for out-of-network care has become more prominent over the last decade. In 2011, 8% of individuals with private insurance used out-of-network care, and 40% of such care involved a surprise bill.[41] In 2014, up to 20% of hospital admissions that originated in emergency departments led to an unexpected bill for out-of-network care.[42] The impact of surprise bills can be substantial enough to lead patients to switch hospitals for subsequent care.[43] Surprise bills may also be a particular challenge in light of the increasing prevalence of HDHPs.[20] Patients with HDHPs may be responsible for the entire cost of their care until a deductible is met, and for patients with plans that cover some out-of-network care, their in-network and out-of-network

deductibles may be different. As of 2018, nine states had adopted laws that provide protection from surprise billing, although these laws do not apply to self-insured employer plans that are regulated by the federal Employee Retirement Income Security Act or to Medicare or Medicaid.[44] At the time of this writing, the US Congress is actively considering federal legislation to address the surprise billing issue.[45]

PROVIDER NETWORKS AND CANCER CARE DELIVERY

Key federal regulations, protections, and gaps regarding health insurance plans for patients with cancer are summarized in Table 1. For insured patients with cancer who have qualified health plans or public insurance, provider network requirements should, at minimum, enable in-network access to oncologic care. Still, a cancer diagnosis confers specific challenges with respect to insurance network adequacy, including access to specialized centers and investigational clinical trials.[46]

Access to Specialized Centers

Depending on diagnosis, geography, and individual preference, patients may wish to seek care at specialized cancer centers or from hospitals with specific expertise in their diseases. Some evidence suggests that care at specialized centers, such as those designated by the National Cancer Institute (NCI), may be associated with improved outcomes for certain types of cancer.[47-51] However, care

TABLE 1. Protections and Gaps in Federal Regulations Regarding Health Insurance for Patients With Cancer

Variable	Protections	Gaps
Coverage requirements	Guaranteed issue: Coverage in qualified health plans cannot be denied on the basis of preexisting conditions	Policy shifts are encouraging enrollment in short-term health plans that lack qualified health plan protections and essential health benefits
	Community rating: Patients in qualified health plans cannot be charged more for preexisting conditions	
	Essential health benefits relevant to cancer:	
	Outpatient care	
	Hospitalization	
	Emergency services	
	Mental health services	
	Prescription drug coverage	
	Laboratory services	
Provider network requirements	Provider networks must provide public directories and ensure sufficient choice of providers	Inconsistent interpretation of sufficient choice, particularly with respect to specialty care
		Regulations that address out-of-network coverage when networks are insufficient are not well defined
		No requirement for in-network access to specialized centers for rare or complex cancer cases
		Specific network requirements and surprise billing rules have varied by state
		Short-term health plans are not subject to network requirements
		Navigating provider network rules may be a substantial burden for patients and families
Cost protections	Annual out-of-pocket maximum provides some protection against catastrophic costs	Out-of-network care may not be counted toward out-of-pocket maximum
	No lifetime or annual limits on coverage	Out-of-pocket maximum may still constitute a catastrophic cost for some patients
		Original fee-for-service Medicare without a supplemental plan has no out-of-pocket maximum
Access to clinical trials	Standard-of-care costs of clinical trial participation must be covered	No requirement that clinical trial sites be included in provider networks
		No federal Medicaid clinical trial coverage requirement

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provided at such centers, some of which are exempt from the prospective payment system used by CMS to determine reimbursement for hospitalizations by diagnosis and may therefore have less incentive to control costs,[52] can be more expensive than care provided in local communities. This may create incentives for insurers to exclude specialized cancer centers from their networks.[46] Indeed, only 41% of provider networks that were initially available on federal marketplace plans included NCI-designated cancer centers,[53] and narrow networks seem to be more likely to exclude oncologists who are affiliated with centers designated by NCI or the National Comprehensive Cancer Network.[14]

Access to Clinical Trials

Before the Affordable Care Act, requirements for insurance coverage for standard-of-care, or routine, costs of clinical trial participation varied by state. Medicare instituted a requirement for coverage of these costs in 2000,[54] and from 2000 to 2010 many states followed suit.[55] The ACA then instituted the first federal requirement for coverage of these costs within private insurance plans.[56] There is currently no federal requirement for clinical trials coverage under Medicaid, though some states require such coverage.

Despite these requirements, provider network structure may constitute a barrier to enrollment in clinical trials. Although insurance plans may be required to cover routine care costs for clinical trial participants, there is no specific requirement that plans provide in-network access to centers or practices that maintain clinical trial programs. As described above, obtaining care out of network can be expensive. If covered at all, such care may require substantial additional cost sharing,[57] and it may not count toward a catastrophic annual limit on out-of-pocket costs. Even if a patient's insurance plan provides for out-of-network access to clinical trials in the absence of an equivalent in-network option, the additional logistical requirements to obtain approval for care at an out-of-network site could constitute an important barrier.

Patient Understanding of Provider Network Rules

The complexity of regulations described above may pose a particular challenge for patients with cancer, who must navigate the health care system while dealing with a life-threatening illness. Even in the absence of a cancer diagnosis, choosing insurance plans and understanding the implications of these choices can be an important challenge. Individuals shopping for insurance may focus predominantly on premium and overall cost rather than on provider networks,[58-60] and narrow network structures may be associated with lower premiums. In this context, patients who are subsequently diagnosed with cancer—rarely an event that a patient would have expected when choosing an insurance plan—may be surprised to learn that their insurance plans do not cover access to preferred oncologists or cancer centers.

OPTIMIZING ACCESS TO AFFORDABLE CANCER CARE

If narrow provider networks may restrict access to specialized care that could improve outcomes, an important policy question is whether insurers should be required to provide access to tertiary care if a network contains an insufficient number or type of specialists. This may be difficult to implement, as such centers may be geographically distant and because such a requirement would likely diminish leverage for payors in contract negotiations with specialized, expensive centers, driving up the costs of care. Requiring payors to include such centers might be a disincentive for payors to participate in individual insurance marketplaces,[61] potentially encouraging the spread of even more limited short-term plans that would not be subject to such requirements. Furthermore, patients who are in need of routine treatment of common cancers may not require access to highly specialized centers. Narrow network plans might reasonably limit providers for common cancers when the network includes multiple highly qualified specialists, but policy efforts may be needed to define the clinical criteria for treatment at specialized centers for which coverage mandates for payors might be proposed. Development of guidelines that define the qualifications for access to specialty care for rare or complex conditions would obviate the prevailing system of case-by-case adjudication and appeals, which are onerous for patients with cancer and their families to navigate. When the care required is highly specialized, as in the case of rare cancers that require complex surgical care, stem-cell transplantation, or novel cellular therapies, narrow network plans should have policies in place for exceptions that allow for coverage of otherwise out-of-network care.

Increasing awareness of health insurance plan structures among patients who are at risk for or diagnosed with cancer and their clinicians could assist patients in navigating a complex provider network landscape. As a cancer trajectory evolves, patients may become eligible for changes in insurance plans, either at their next open enrollment period or because of changes in life circumstances as a result of medical or financial toxicities. Financial and oncology nurse navigators play an important role in assisting patients with financial navigation, including navigating health insurance barriers to care.[62] Particularly in settings in which navigation resources are not readily available, it is incumbent on oncologists to have a basic understanding of the regulations governing insurance networks so that they may advise patients appropriately. Clinicians should recognize and acknowledge the considerable burden that falls on patients and their families, who may spend a great deal of time negotiating with insurers on the extent to which services will be covered.

In conclusion, in an effort to control health care costs, insurers contract with in-network providers to deliver care at negotiated rates, restricting access to out-of-network providers by denying or reducing coverage. Patients with cancer and their caregivers already cope with anxiety and uncertainty

surrounding a cancer diagnosis, symptoms of disease, and medical and financial toxicities[63] of therapy. The need to navigate a complex health care system at the same time is likely a substantial challenge for many patients, who may not fully understand the implications of their health coverage choices with respect to options for care for serious illness—or who may not be able to afford the higher premiums charged by plans that offer more choice in providers. Policy efforts should focus on developing regulations that govern insurance plans that balance the dual goals of keeping health care affordable and optimizing access to cancer and other specialty care. In the meantime, patients and providers need access to clear information about the implications of their health insurance choices for access to cancer care.

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