

Navigating the Coverage Experience and Financial Challenges for Cancer Patients:

Affordable Care Act Brings Improvements, But Challenges Remain

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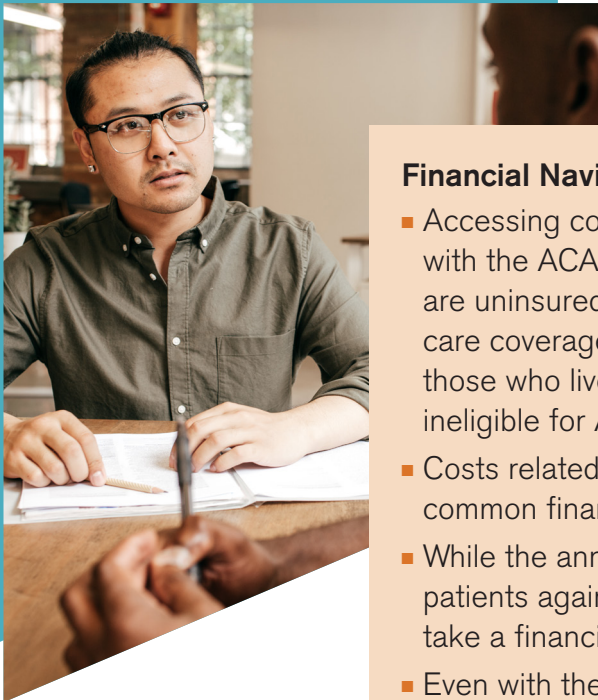


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Summary

The Affordable Care Act (ACA) guarantees coverage to individuals with pre-existing conditions, offering cancer patients and survivors a lifeline to accessing treatment. And while the ACA ushered in important consumer protections, particularly for cancer patients who require high-cost care, patients continue to face high out-of-pocket costs and hurdles to obtaining recommended treatments.

Financial Navigators are hospital or health-system staff that work with cancer patients to review their plan options, understand their coverage, and obtain treatment. Due to their close work with cancer patients as they obtain treatment, Financial Navigators provide insights into how private insurance coverage under the ACA is working to give their patients access to care.



Financial Navigators reported:

- Accessing comprehensive coverage has significantly improved with the ACA marketplaces and reform, particularly for people who are uninsured and for those who unexpectedly lose their health care coverage. However, obtaining coverage is still difficult for those who live in states that haven't expanded Medicaid or are ineligible for ACA-related financial assistance.
- Costs related to using coverage—not premiums—remain the most common financial barrier for their patients.
- While the annual limit on out-of-pocket costs provides security to patients against catastrophic costs, meeting that limit annually can take a financial toll.
- Even with the help of a Financial Navigator, it's difficult to get information on what a patient can expect to pay out-of-pocket for treatment.
- Although cancer treatment is more likely than ever to be covered, the practice of “medical management” has become more prevalent.
- Network adequacy varies, depending on local market dynamics, but when patients lose access to a covered provider, ensuring continuity of care is critical.
- Limited health literacy and high-level plan summaries make it difficult to understand plan rules for obtaining treatment.

Introduction

The Affordable Care Act instituted sweeping changes to health coverage in the United States. The law establishes a federal floor of consumer protections for those buying private health insurance on their own or through a small employer, and provides federal financial assistance for eligible individuals buying individual coverage through health insurance marketplaces. Seven years after the law was signed, 20 million individuals—many of them cancer patients and survivors—have gained coverage and more than 150 million people with job-based coverage have improved protections against catastrophic health care costs.¹

For the approximately 15 million people living with cancer, having health insurance coverage is a lifeline to accessing treatment.² Prior to the ACA, getting coverage outside of employment was difficult for anyone in less-than-perfect health but particularly so for those with a personal or family history of cancer.³ The ACA changed that with insurance market rules that prohibit insurers from denying coverage, excluding benefits, or charging higher premiums based on an individual's health status.

However, even with coverage, many cancer patients and survivors experience financial hardship because of the costs associated with treating cancer.⁴ Higher cost-sharing—in the form of higher deductibles, coinsurance, and copayment amounts—has increasingly shifted costs to patients at a time when cancer remains one of the most expensive diseases to treat.

While each cancer patient's experience is different, many face similar challenges when it comes to navigating health insurance. Getting a cancer diagnosis is often a shock and requires patients to understand not only their treatment options, but how their health plan works in terms of the coverage it provides. For some patients, this may be the first time that they or their family has ever had to fully comprehend the scope of their health insurance. And a cancer diagnosis affects not only the patient, but the patient's whole family: many cancer patients—and their caregivers—have to reduce their hours at work, take unpaid time off for caregiving, or stop work entirely as a result of the illness. Consequently, a cancer patient's household income may drop dramatically just as big health care bills hit. Compounding that, cancer patients often need services that health insurance typically does not cover, including support services like transportation to treatments, meals, and general caregiving services at home.⁵ These services can put an additional strain on family caregivers and household expenses.

To help alleviate the financial distress that a cancer diagnosis and treatment can cause, some hospitals have established Financial Navigator programs to help their cancer patients through the complexity of the coverage and cost of cancer treatment.⁶ Financial Navigators work with patients who have all types of coverage, including Medicare, Medicaid, marketplace plans, and employer-sponsored coverage, as well as those without insurance. Through one-on-one counseling, Financial Navigators help newly diagnosed cancer patients understand their out-of-pocket costs and the rules for obtaining services, help them obtain approval for treatments and services that require prior approval, and connect them to foundations or programs that help pay for costs not covered by their insurance. Financial Navigators may also help patients evaluate their coverage options and enroll them in coverage that best suits their income and treatment needs. Often, these Financial Navigators become the liaison between patients and their medical providers, health plan, and other hospital departments like billing and the pharmacy.⁷

To better understand the experience of privately insured cancer patients, researchers interviewed Financial Navigators who assist cancer patients with navigating their health insurance coverage and treatment. The Financial Navigators that researchers interviewed had various backgrounds, but most trained as social workers or nurses. Some are also certified application counselors who are trained

“We social workers started recognizing that a lot more of the concerns that the patients were bringing to us were financial in nature. We evolved with the needs of our patients.”

Note: All quotes included in this report are taken from interviews with Financial Navigators

to help individuals enroll in marketplace coverage. Many previously held positions at their hospitals in different departments like insurance verification or hospital billing before taking on their current roles. Titles also varied across the respondents: most have the title of Financial Navigator or Oncology Navigator, but others have the title of Senior Financial Specialist, Clinical Financial Consultant, or Oncology Social Worker. This paper discusses the results of these interviews and what they reveal about how cancer patients access care, the adequacy and affordability of covered services, and the transparency of plan information.

Methodology

This paper summarizes the experiences of cancer patients who have worked with Financial Navigators at 11 U.S. hospitals in nine states. These states are California, Colorado, Illinois, Massachusetts, Michigan, Pennsylvania, South Carolina, Tennessee, and Wisconsin. Researchers conducted structured interviews with 13 Financial Navigators⁸ at 11 hospitals, focusing on the experience of patients with private insurance, either purchased on their own or obtained through an employer plan. Hospital location and the population size served varied, ranging from hospitals located in mid-size to large cities to those in less populated, rural areas. It is important to note that while hospital-based Financial Navigators interact with many cancer patients, their experience is not representative of all cancer patients. Not all cancer patients receive cancer treatments (i.e., chemotherapy, surgery) in a hospital setting.

Researchers conducted their interviews in January and February 2017. At the time the interviews were conducted, the new Congress began to debate changes to the ACA that would potentially affect the coverage options and consumer protections discussed here.

Understanding the Coverage Experience for Cancer Patients: Access and Availability

Prior to the ACA, those without access to coverage through an employer or through public programs faced significant barriers to obtaining affordable, adequate health insurance.⁹ Cancer patients who lost coverage under their employer plan due to reduced hours or job loss could continue their coverage through COBRA¹⁰, but premiums could be prohibitively expensive, particularly on a reduced income. In addition, coverage through the individual market or a high-risk pool, when available to cancer patients, came with benefit exclusions, unaffordable premiums and deductibles, and dollar limits on covered services. The ACA now guarantees coverage to individuals regardless of health status, giving cancer patients the security of comprehensive coverage in the individual market when insurance under an employer plan or other source is not available.

“I think the major issue [with access] is that we didn’t expand Medicaid. And that hurts a lot of people in this area.”

The Financial Navigators almost universally reported that getting coverage for patients without insurance or those losing their coverage has improved significantly since enactment of the ACA. Financial Navigators can enroll uninsured patients in individual coverage during the annual open enrollment period, and those losing other coverage can enroll through a special enrollment period. However, Financial Navigators in states that haven’t expanded Medicaid said they have uninsured patients who aren’t eligible for Medicaid but have income that is not high enough to qualify for financial assistance in the marketplace. Patients in that circumstance must rely on uncompensated care and charity programs if available.

Cancer patients also have new options and more flexibility under the ACA. For instance, cancer patients who lose employer-sponsored coverage can choose between COBRA and an individual policy, potentially with financial assistance for a marketplace plan. And those who qualify for Medicare based on disability but face a two-year wait for benefits to begin can enroll in a marketplace plan to fill the gap.

For those who have a choice of COBRA or a marketplace plan, Financial Navigators help patients compare their options, taking into account more than plan costs. They look at the timing of enrollment, the patient's household income, and where they are in their course of treatment. For example, if the patient has already met the out-of-pocket limit under an employer plan, Financial Navigators will account for the cost to switch to a new plan with a new deductible and new out-of-pocket limit to meet. Similarly, if the patient is in the middle of treatment she may benefit more from staying in her current plan rather than risk disruption under the coverage rules of a new plan. And for those with lower or moderate incomes, particularly following the loss of a job, a marketplace plan may be the best option because of financial assistance in the form of lower premiums and reduced out-of-pocket costs. "You're trying to lay out a lot of things; it's complicated, more than a math kind of thing" said one Financial Navigator.

Financial Navigators reported that the cancer patients with whom they work are very likely to maintain their coverage because they understand that treatment would be unaffordable without health insurance. When comparing plans, Financial Navigators urge patients to consider whether the premium is affordable, and hospitals help confirm coverage. "What is unique with the cancer patients is that they have pretty regular treatments, so we do tend to check coverage monthly just to ensure a patient's coverage is still there," said a Financial Navigator.

Understanding the Coverage Experience for Cancer Patients: Affordability

Prior to the ACA, people who tried to buy health insurance on the individual market often found premiums unaffordable and out-of-pocket costs prohibitively expensive. The ACA helps make individual market coverage more affordable for low- and moderate-income consumers by providing subsidies for premiums and out-of-pocket costs. The law also requires all plans, including employer-based plans, to cap annual out-of-pocket costs.

Financial Navigators reported that costs related to using coverage—not premiums—remain the most common financial barrier for their patients. The main financial barrier to accessing care with insurance coverage is the high annual limit on out-of-pocket spending—up to \$7,150 for an individual plan and \$14,300 for a family plan in 2017¹¹—and, to a lesser extent, high deductibles. Because of the substantial costs to treat cancer, most patients meet the deductible and out-of-pocket limit quickly.

While the annual limit on out-of-pocket costs provides security to patients against catastrophic costs, meeting that limit annually—and often in a very short time—can take a financial toll. As most health plans use a calendar year for out-of-pocket costs like deductibles and the out-of-pocket limit, the clock resets on these payments each January. As a result, the timing of a cancer diagnosis significantly impacts a patient's ability to cover their out-of-pocket costs. As one Financial Navigator noted, "unfortunately for those that are diagnosed toward the end of the year, [they] have to meet their deductible and begin again in January." Since cancer patients must often meet deductibles and pay maximum out-of-pocket costs three to four years in a row, depending on the length of cancer treatment, this back-to-back

"Year one with a diagnosis, most of the out-of-pocket costs go towards the work-up: imaging, biopsy, and surgery. If that happens in June, we know the out-of-pocket limit resets the next year . . . when [the] patient is in active treatment with chemotherapy."

yearly expense when accessing care becomes a huge financial expense. According to one Financial Navigator, “the average people I work with don’t have money saved and if they do, it’s minimal. Having to meet out-of-pocket costs three years in a row—it’s \$15,000, not \$5,000.”

Most cancer patients face high out-of-pocket costs, regardless of the type of private coverage they have. However, those patients who don’t qualify for financial assistance—in particular, cost-sharing reductions—for marketplace plans have the greatest difficulty affording coverage and out-of-pocket costs. One Financial Navigator said patients in that circumstance typically can only afford to buy low-premium, high-deductible plans, noting, “they can’t afford any of it except the premiums.”

“We’re dealing with a population that will work less, or the family is losing a breadwinner, so the out-of-pocket cost is a barrier when they have to put food on the table and pay for transportation and utilities.”

Income constraints—because of job loss or unexpected financial costs that often accompany a cancer diagnosis—compound the financial burden of paying high out-of-pocket costs and the often fragile financial situation in which cancer patients find themselves. For instance, working-age patients may find that their income is reduced or non-existent as a result of their diagnosis, often placing an additional strain on existing financial obligations to children or aging parents. At the same time, patients who are retired and living on a fixed income struggle with the unexpected costs of care with their budgets. Patients across the spectrum may be limited in their ability to cover thousands of dollars in out-of-pocket medical expenses while undergoing treatment.

Financial Navigators employ an array of strategies to help patients manage their out-of-pocket costs. Some help their patients get estimates of the cost of their procedures and related out-of-pocket costs, particularly coinsurance amounts, before the procedure happens. Doing so, however, can be challenging even for these hospital-based advocates: one Financial Navigator described it as a “grueling process” because rates vary by plan. Others noted getting an estimate may require information that a patient may not easily obtain, such as a billing code. Financial Navigators also help patients take advantage of financial assistance programs at hospitals, foundations, or drug manufacturers, and some hospitals allow patients to establish an installment plan for out-of-pocket costs so that payments can be spread out. In some cases, however, patients may delay treatment, get an alternative or less than optimal treatment, or skip medications because of cost.

Understanding the Coverage Experience for Cancer Patients: Adequacy

Before the ACA, state rules on benefit standards varied significantly. Individual market plans often excluded coverage for critical benefits, such as prescription drug coverage.¹² And many health plans, including employer-sponsored coverage, had annual dollar caps on the benefits that they did cover.¹³ For cancer patients, these annual coverage limits would expose them to catastrophic costs for their treatment.¹⁴ The ACA helped close these gaps by requiring plans sold to individuals and small employers to cover a minimum set of essential health benefits, including prescription drugs. In addition, individual and employer-sponsored health plans can no longer impose an annual or lifetime dollar cap on essential benefits under the ACA.

A majority of Financial Navigators indicated that most cancer treatment is now covered. Benefit exclusions generally do not exist for their patients’ cancer treatment, although a few Financial Navigators noted exclusions for services like genetic testing, molecular pathology, or certain forms of radiation therapy such as proton therapy. Although cancer treatment is more likely than ever to be covered, most Financial Navigators reported that the practice of “medical management” has increasingly become an obstacle to patient care and some reported concerns about the adequacy of plan networks.

Medical management. Financial Navigators particularly cited medical management requirements such as prior authorization for services and step therapy for prescription drugs, which requires a patient to first try a lower-cost drug before accessing a higher-cost drug. Many Financial Navigators noted the use of prior authorization has become “a big issue.” One Financial Navigator remarked that when he started working, only a “select few of [their] insurers” required prior authorization for obtaining care, but now most plans require prior authorization.

While prior authorization sometimes is applied to radiation therapy, Financial Navigators reported that higher-cost oral chemotherapy drugs and newer cancer drugs are most commonly subject to prior authorizations or step therapy. “Oral chemotherapy is a huge issue—it’s pretty common that you’ll need prior authorization,” stated one Financial Navigator. Another noted that “cutting-edge cancer drugs are on the formulary, but have limitations” like step therapy or are placed on the highest cost-sharing tier. One of the problems with newer, cutting-edge drugs is that the insurer may not have a billing code or medical policy for that particular treatment; as one Financial Navigator noted, “the insurer may not be familiar with that drug yet.” For patients who change plans or plans that change their medical management policies, step therapy requirements present administrative obstacles to ongoing treatment. As one Financial Navigator said, “You’ve got these medications, and for patients, maybe it’s been working for them for some time. They get renewed (in a plan) or get a new plan, and all of a sudden it becomes a problem that they haven’t taken Drug A first.”

“For more and more of our insurers, [prior] authorization is a big issue.”

Medical management did not appear to be more prevalent in particular types of coverage; rather, as one Financial Navigator, noted, “it’s more about the drug.” Financial Navigators reported appealing denials and facilitating peer-to-peer reviews in order to get insurers to approve cancer drugs and therapies. While Financial Navigators indicated that they are usually successful in getting cancer drug therapies approved, the process “creates a huge barrier as far as waiting for our patients.” In some instances in which the providers want to use a drug off-label to treat patients, Financial Navigators request exceptions to get the drug approved. If they are unsuccessful in obtaining approval for a recommended drug, Financial Navigators indicate that most patients still get treatment, but may not be getting the “most potent” treatment that their providers want. In general, providers are usually able to obtain final approval for a service or treatment, but it often requires assistance from Financial Navigators or other hospital departments with more experience with plan rules and processes: “it’s a hoop you have to jump through.”

Network adequacy. Financial Navigators did not universally identify health plan networks as a barrier to care for cancer patients. This may be due, in part, to the upfront work the hospitals do to confirm coverage under patients’ plans and the role of Financial Navigators in helping patients understand their network limits and costs. In addition, whether or not provider networks were seen as adequate varied depending upon where the hospital or health system is located and the local market dynamics.

For Financial Navigators in large health systems in a more rural area, for instance, network adequacy is not an issue for their patients. As one Financial Navigator remarked, “we’re the only player in town so most [marketplace] and employer plans, we participate in.” For other systems, particularly hospital systems in areas with competing providers, network adequacy may be an issue. One Financial Navigator working in an area with many hospitals and health systems noted that her health system had been excluded from some health plans. A Financial Navigator in an area served by multiple hospital systems indicated that her health system was a second-tier provider on many marketplace plans: for her, working with those patients involves “tricky conversations because they can come but they’ll have to pay more.”

When providers are no longer in-network because a patient has changed plans or the network for their plan has changed, some Financial Navigators indicated that they work with their insurers on a case-by-case basis to ensure continued coverage of their providers in the hospital. One Financial Navigator noted that insurers will typically work with her on her requests for continuity of care if the patient is in the middle of treatment. Another Financial Navigator shared that as long as the patient has received

an initial diagnosis from the health care system, he can generally help the patient continue covered treatment. This opportunity to continue a patient's care is consistent with some state laws, which allow patients to continue using a provider for treatment for a specified period of time even if the provider is no longer part of their health plan's network.¹⁵

Understanding the Coverage Experience for Cancer Patients: Transparency

Prior to the ACA, consumers had access to relatively limited information about each plan that differed from insurer to insurer, making it difficult to do an apples-to-apples comparison of plan options. The ACA requires all insurers and health plans, including employer-sponsored plans, to provide enrollees and applicants with a Summary of Benefits and Coverage (SBC), which is a standard template that conveys plan features such as cost-sharing, plan exceptions, and rules for accessing care. The SBC, along with the standard metal levels of coverage required under the ACA, is intended to help make plan comparisons easier for consumers.

Even with these new tools, however, Financial Navigators find that cancer patients continue to need one-on-one education to understand basic insurance terms, how out-of-pocket costs apply to their care, and their plan's rules for accessing treatment. "It's like insurance is an entirely different language," said one. Consumers with job-based coverage often had higher health insurance literacy, at least anecdotally and especially when compared to those who only recently became insured. But Financial Navigators consistently reported acute health literacy challenges for all cancer patients, due in part to a lack of transparency on behalf of plans.

A cancer diagnosis can overwhelm patients and make it more difficult to understand what their plan will and will not cover and what their out-of-pocket expenses will be. Furthermore, simple plan explanations often don't provide enough detail to understand how cancer treatment will be covered, especially when care requires physician services, surgery, radiation, lab work, imaging, oral prescriptions, and infusions, among other services. This uncertainty exposes patients to financial risk: patients who get treatment without following plan rules by, for example, failing to obtain prior authorization risk significant costs if coverage is denied.

Financial Navigators help patients understand and follow their plan rules, and will help get approval for services through processes such as appeals, formulary exceptions and peer-to-peer reviews. These rules may be difficult to identify using only high-level plan summaries, and even more difficult to comply with, sometimes resulting in delayed care or higher cost-sharing for patients.

"There is so much with cancer, when you're looking up how chemo or radiation is covered, you have to go deeper; it's not on the fact sheet with cost-sharing. You have to go deeper into [the] policy on how things are paid."

Conclusion

Under the ACA, cancer patients and survivors, along with millions of Americans with chronic conditions, can obtain quality health insurance coverage that provides financial protection for high-cost care. The ACA guarantee of coverage regardless of health status, with financial assistance for low- and moderate-income families, has meant cancer patients can obtain coverage if they lack insurance or are losing employer-sponsored coverage and are not yet eligible for Medicare.

However, even with coverage, many cancer patients continue to struggle with high out-of-pocket costs and barriers to recommended treatments. In their role assisting cancer patients at hospitals across the country, Financial Navigators provide critical insight into the coverage experience faced by many cancer patients. In particular, Financial Navigators highlighted the need to help patients better assess their anticipated costs and obtain approval under their plan's rules for accessing coverage. Given the hands-on help provided by Financial Navigators, it's likely that patients who don't have that assistance would have far greater difficulty getting cost information and overcoming barriers to treatment.

Even with help understanding treatment costs and plan rules, cancer patients struggle with costs. The ACA annual limit on out-of-pocket costs provides critical protection against catastrophic costs, but it still requires patients to meet substantial cost-sharing that can quickly add up to unmanageable costs year after year.

As policymakers consider changes to the ACA, it's important to note that the issues identified through these interviews are those of people with coverage, with the financial protection of an annual out-of-pocket limit and, in some cases, substantial financial help for premiums and out-of-pocket costs. Several proposals under discussion to repeal and replace the ACA would undercut the gains cancer patients have made under the law. Cancer patients and survivors who are uninsured or losing job-based coverage could lose guaranteed access to comprehensive, affordable coverage under proposals to weaken the ACA's protections for people with pre-existing conditions. Access to prescription drugs and other essential services could be at risk if insurers are granted greater flexibility to define covered benefits. And coverage could become unaffordable for many more people living with cancer if premium tax credits are scaled back, the ACA's out-of-pocket assistance is eliminated, or the age rating is expanded. Finally, even those cancer patients and survivors with comprehensive job-based coverage could be hit with catastrophic costs and limited benefits if the ACA's annual cap on out-of-pocket costs and prohibition on annual and lifetime limits are weakened or eliminated.

If these ACA protections are rolled back, people living with cancer would have very different experiences from those identified in this paper. Most significantly, without the lifeline that coverage offers, patients would have difficulty getting any treatment at all.

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