Out-of-Pocket Spending Under the Affordable Care Act for Patients With Cancer

Matthew S. Dixon, PharmD, Ashley L. Cole, MPH, and Stacie B. Dusetzina, PhD

Abstract: The Patient Protection and Affordable Care Act (ACA) included several key provisions aimed at lowering the out-of-pocket cost burden for patients. In this review, we summarize the effect of 3 provisions under Medicaid, Medicare, and commercial insurance, respectively: expansion of Medicaid eligibility, closing the doughnut hole for Medicare Part D beneficiaries, and requiring an annual limit on out-of-pocket spending for commercially insured patients. Through this review, we find early evidence that these 3 ACA provisions have reduced the out-of-pocket burden or increased access to health insurance for many patients. Proposals to repeal and replace the ACA should consider retaining some of these important features that limit financial exposure for patients. At the same time, we have highlighted some important gaps left by the ACA that could be targeted by replacement plans. Addressing these issues may help to increase access to care and affordability for patients with cancer and without.

Key Words: Cancer, Medicaid, cost sharing, drug prescriptions, insurance coverage, medically uninsured, Medicare Part D, Patient Protection and Affordable Care Act

Cancer is the second most common cause of death in the United States, accounting for more than 500,000 deaths and 1.6 million newly diagnosed cases in 2016.1 Furthermore, health care spending on cancer treatment, including anticancer medications, has increased substantially over time,2 3 and treatment costs are expected to continue to rise as innovative new treatments are developed. As a consequence, patients with cancer are at a greater risk of financial toxicity and adverse effects due to high out-of-pocket health care costs compared with patients with many other chronic disease states.4 For patients with cancer, high out-of-pocket costs are associated with financial hardship, negative clinical outcomes, decreased health-related quality of life, and decreased treatment adherence.5 6

Thankfully, the Patient Protection and Affordable Care Act (ACA) included several provisions aimed at reducing out-of-pocket spending for patients. In this review, we outline the effects of the ACA on out-of-pocket treatment costs for patients with cancer, including a summary of remaining gaps in affordability for patients. We focus on 3 provisions for patients covered under Medicaid, Medicare, and commercial insurance, respectively: the expansion of eligibility for Medicaid, the closing of the doughnut hole for Medicare Part D beneficiaries, and the annual limit on out-of-pocket spending for commercially insured patients.

Medicaid: Expansion of Coverage

Medicaid is the largest public health insurance program for people with low income in the United States, covering 1 in 5 people in 2016.10 Medicaid and the Children’s Health Insurance Program provide coverage at little to no out-of-pocket cost for low-income persons in the following groups: infants and children, parents, pregnant women, senior citizens, and disabled persons of all ages.10 The federal and state government jointly fund Medicaid, with guaranteed federal matching based on per-capita income.11 Prior to Medicaid expansion under the ACA, pregnant women and children were eligible for Medicaid if they had incomes between 100% to 133% of the federal poverty level (FPL), but eligibility levels for parents could be lower, and states were not required to cover childless adults.12 The ACA sought to expand Medicaid eligibility to all individuals at or below 138% FPL by 2014 (currently $16,394/individual, $27,821/family of 3).13 However, in 2012, the Supreme Court determined that Medicaid expansion would be optional for states, and as of January 2017, 31 states and Washington, DC, had expanded Medicaid, and 19 states had not.10 14

Impact of Medicaid Expansion on Out-of-Pocket Spending

For Medicaid programs offering prescription drug coverage, they must include drugs for which the manufacturer has entered into a rebate agreement with the Secretary of Health and Human Services.15 States may implement a formulary or preferred drug list with nominal copayments for prescriptions (e.g., $4/preferred, $8/nonpreferred),16 limiting out-of-pocket exposure for patients.2 7 This is paramount because patients with cancer are more likely to delay or forego medical care because of financial difficulty, compared with the general population.17 In addition, states that expanded Medicaid must also include preventive cancer screenings as part of the 10 essential health benefits of the ACA.18

A recent study by Mulcahy and colleagues19 showed that people who transitioned from no coverage to Medicaid coverage after expansion had an average of 13.3 more prescription fills in the subsequent year (a 79% increase). Patients with breast cancer within the study faced significantly lower out-of-pocket costs when transitioning from no coverage to Medicaid, with average out-of-pocket spending for endocrine therapy decreasing by roughly $200.19 A study by Ghosh and colleagues20 found that overall drug utilization increased by 19% in Medicaid expansion states relative to nonexpansion states in the 15 months following the ACA expansion. These results suggest that Medicaid expansion increased access to care and lowered out-of-pocket costs for enrollees needing prescription drugs.

Recent studies have also shown that enrollees in expansion states have increased utilization of preventive services.21 Results from the Oregon Health Insurance Experiment showed that in the year after acquiring coverage new Medicaid members were more likely to undergo certain recommended cancer screenings compared with those not selected for Medicaid enrollment.22
The largest effects were seen for colorectal cancer screening and cancer screenings for women with elevated cancer risk.22

Remaining Challenges for Medicaid Beneficiaries

For individuals living in the 19 states that did not expand Medicaid, eligibility criteria include a median income limit of 44% FPL for a family of 3, with a range of 18% to 105%.23,24 Furthermore, childless adults remain ineligible for coverage in 18 of the 19 nonexpansion states, with limited coverage for some adults in Utah and Oklahoma.24 Perhaps even more concerning, in these states, 2.6 million adults fall into a “coverage gap” of having incomes above the Medicaid eligibility limit for their states but below the 100% FPL eligibility threshold for low-income subsidies for marketplace plans, putting insurance coverage out of reach for most of these individuals (Fig. 1).23 Furthermore, while out-of-pocket costs for Medicaid enrollees are low relative to the prices of many cancer treatments, it is important to recognize that any cost sharing may serve as a barrier for accessing care for patients with low incomes.

Medicare Part D: Closing the Doughnut Hole

Since 2006, Medicare Part D has been a reliable source of outpatient prescription drug coverage for seniors, covering nearly 41 million Medicare beneficiaries as of 2016.25 However, the original Part D benefit design included a coverage gap (the so-called “doughnut hole”), in which patients were responsible for 100% of their prescription drug costs after exceeding the initial coverage limit and until they reached the catastrophic coverage limit. For many patients taking chronic or specialty medications, the doughnut hole created a large and unexpected financial burden.26,27

At the same time that Medicare Part D was expanding prescription drug coverage among older adults, the number of orally administered cancer medications nearly tripled, with many more in the pipeline.28 This has shifted insurance coverage for many anticancer medications to the prescription drug benefit (Part D), increasing the importance of Part D coverage for older adults with cancer over time.29

A key provision of the ACA for Medicare beneficiaries was closing the doughnut hole. This reduces patient out-of-pocket spending on drugs filled while in the doughnut hole from 100% before 2010 to 25% by 2020 (Fig. 2). In 2010, the standard plan design consisted of a $310 deductible, an initial coverage phase in which the patient paid a 25% coinsurance, and the plan covered the remaining 75%, until total drug spending exceeded $2830. After meeting the initial coverage limit, the patient entered the doughnut hole, paying 100% of drug costs until they reached $4550 in out-of-pocket spending. From that point on, patients pay 5% of total prescription drug costs, Medicare pays 85%, and the Part D plan sponsor pays 15%. The benefit structure resets at the beginning of each calendar year. Figure 3 shows the out-of-pocket amounts required to move through each benefit phase, beginning in 2010 (leftmost bar, prior to the closure of the doughnut hole) through 2017.

With the ACA, the payment structure of the doughnut hole changed in 3 key ways, beginning in 2011. First, for generic medications, patients’ out-of-pocket costs are gradually offset by the

FIGURE 1. Comparison of Medicaid coverage in expansion and nonexpansion states using the median Medicaid eligibility limits for nonexpansion states in 2016.

Part D plan sponsor, ultimately reducing to patients paying 25% and plans 75% of the drug price in 2020 (Fig. 4A).5,6 Second, for branded drugs, patient cost sharing is reduced and offset by the plan and a 50% manufacturer discount (Fig. 4B). Finally, for branded drugs, the manufacturer discount is credited toward patients’ out-of-pocket spending, allowing patients to move through the doughnut hole more quickly.30

Impact on Patient Out-of-Pocket Spending

Closing the doughnut hole means patients will pay less out-of-pocket for the same quantity of medication, because of lower cost sharing in the doughnut hole. As of 2014, this policy has collectively saved patients more than $11.5 billion.32 However, savings from cost-sharing reductions in the doughnut hole may be limited relative to the total out-of-pocket cost for users of many orally administered anticancer therapies. This was demonstrated in an analysis performed by Dusetzina and Keating,6 which found that although patients will save approximately $2550 annually in out-of-pocket costs for orally administered anticancer medications under the 2020 doughnut hole structure, they will still pay between $3889 and $9623 in cost sharing for the duration of therapy. Notably, a large proportion of spending for Medicare Part D beneficiaries using specialty drugs is under the catastrophic phase (where the beneficiary pays 5% of the drug price). Although this is relatively small percentage, the high price of most oral anticancer drugs can result in significant spending by beneficiaries each calendar year.32 Furthermore, patients trying to mitigate their out-of-pocket burden through plan selection may have few options, as coverage for orally administered anticancer therapies varied little across Part D plans.6

Remaining Challenges for Medicare Beneficiaries

While closing the doughnut hole has provided relief for many seniors, a few key challenges remain. Emerging research has shown that the high price of anticancer medications and the Part D benefit design have resulted in patients being exposed to very high out-of-pocket spending over time.5,7,33,34 Importantly, there is currently no limit on out-of-pocket spending on outpatient prescription drugs on Medicare Part D plans (including Medicare Advantage plans). Trish and colleagues34 explored this by investigating Medicare Part D expenditures for patients taking specialty medications before (2008–2010) and after (2011–2012) initiation of doughnut hole closure. They found that, while mean out-of-pocket spending below the catastrophic threshold decreased by 26% after 2011 compared with before, these savings were almost entirely offset by out-of-pocket spending in the catastrophic phase, which increased by 92% in the post-ACA period. Limiting spending by seniors across all part of their health care spending should be a goal of future policy-reform efforts.

Next, additional costs incurred by Part D plan sponsors and Medicare may result in increases in premiums over time for all enrollees. This stems not only from the increasing proportion of costs covered by plans in the doughnut hole (up to 75% for generic medications and 25% for branded medications), but also from the higher proportion of beneficiaries who will likely reach the catastrophic coverage phase (where the plan is responsible for 15% of drug costs; Fig. 2).

The impact of closing the doughnut hole on premiums after 2020 will depend on the number of beneficiaries who make it to the doughnut hole and catastrophic phases, as well as other factors in the pharmaceutical market. Surprisingly, between 2011 and 2015, average Part D premiums were relatively flat or decreasing,35 possibly stemming from overestimation of costs by plans in the prior year and subsequent equalization via risk corridors.36 However, 2016 saw a 6% increase in premiums—the highest since 2009—as well as the highest increase in deductibles in Part D’s history.35

Commercial Insurance: Annual Out-of-Pocket Spending Limits

The ACA included many provisions aimed at the commercial insurance market, including individual and employer-sponsored commercial plans. Perhaps the most critical provision for patients undergoing cancer treatment is the requirement that all plans be subject to annual out-of-pocket spending limits. Starting on January 1, 2014, the ACA required all nongrandfathered group health plans to comply with annual limits on out-of-pocket spending.37,38 Spending that contributes to the out-of-pocket limit includes coinsurance, copayments, and deductibles paid for in-network medical or pharmacy services.39 The out-of-pocket limit is the total amount an enrollee will have to pay during a
policy period before his/her health insurance plan begins to cover 100% of his/her essential benefits.18

For 2017, the out-of-pocket limit is $7150/individual and $14,300/family.37 Although this limit shields patients from extremely high annual out-of-pocket spending, affordability is also dependent on the structure of cost sharing within the health plans. For example, high deductible plans that have front-loaded out-of-pocket spending can create a substantial financial burden for patients with cancer during their initial months of treatment.

**Employer-Sponsored Health Plans**

In 2016, 98% of employer-sponsored plans had out-of-pocket spending limits, but there was considerable variation in the dollar amounts for the limits.40 Among single enrollees, 14% had out-of-pocket limits of less than $2000, 18% had limits greater than $6000, and the remaining 68% fell somewhere between.40 Enrollees in employer-sponsored plans have also experienced a shift in how they pay for their prescription drugs with increased use of deductibles and coinsurance over the past decade. An analysis of large employer plan enrollees found that in 2014 24% of out-of-pocket prescription drug expenses were paid through deductibles compared with only 4% in 2004.41 In addition, 20% of out-of-pocket drug expenses in 2014 were paid through coinsurance, compared with 3% in 2004.41

**Marketplace Exchange Plans**

Insurers selling plans within the ACA marketplace are required to reduce cost sharing for low- and moderate-income subsidy-eligible enrollees in Silver plans.37 For example, 2015 enrollees with an income between 100% and 200% FPL had out-of-pocket limits of $2250/individual and $4500/family, whereas enrollees between 200% and 250% FPL had limits of $5200/individual and $10,400/family.37 As with large employer-sponsored insurance, the enrollee’s out-of-pocket limit protects them from high annual spending, but the degree of protection also depends on the plan’s makeup of deductibles, copayments, and coinsurance.42 Like group plans, there is considerable variation in coverage within exchange plans. The median 2016 maximum out-of-pocket limit for Silver plan enrollees without subsidies is $6500, with a range of $4000 to $6850.42

For exchange plans with lower actuarial values, such as the Bronze plan, enrollees typically have higher cost sharing because of deductibles and coinsurance, which enables these plans to set lower premiums.43 Therefore, many enrollees initially select Bronze or Silver plans with low premiums.44 However, patients with cancer may financially benefit from paying a higher premium for a plan with lower deductibles and less coinsurance because many orally administered anticancer drugs are placed on the highest cost-sharing specialty tier,44,45 and this practice is increasing over time.43

**Remaining Challenges for Commercially Insured Patients**

Overall, the out-of-pocket maximum provision has been a positive development for patients with cancer. However, the shift toward the use of high deductibles and coinsurance may limit patient access to treatments. This is of particular concern for patients who need ongoing expensive treatments year after year.

In addition, a large proportion of commercially insured enrollees do not have enough liquid assets to meet the maximum out-of-pocket limit.46 A 2015 report analyzed how household resources match up against the potential out-of-pocket limits introduced by the ACA.46 Two hypothetical out-of-pocket limits were used to represent the middle to high range of out-of-pocket cost sharing seen in commercial insurance plans: $3000 single/$6000 family (middle limit) and $6000 single/$12,000 family (high limit), respectively. They found that 39% of commercially insured households lacked the liquid financial assets needed to cover the middle limit, and 51% were unable to cover the high limit.46 Moreover, 71% of those in the 100% to 250% FPL reported lacking liquid assets to cover for the middle limit, and 82% the higher limit.46

**DISCUSSION**

The 3 ACA provisions outlined in this review have reduced the out-of-pocket burden or increased access to health insurance for many patients, but some important gaps in coverage and access remain. Medicaid expansion has increased insurance access to millions of previously uninsured Americans. Early studies of the impact of Medicaid expansion suggest that it has increased access to treatments and reduced costs for patients with cancer.19,20 In addition, the coverage of preventive cancer screenings has increased the use of such services within the low-income population, potentially leading to increased early detection and treatment.19–22 Nevertheless, approximately 3 million people remain in the coverage gap in states that refused Medicaid expansion, putting health insurance coverage out of reach for most of these individuals. This is a critical area for improvement as health care reform is explored in early 2017.

For Medicare beneficiaries, closing the doughnut hole lowers out-of-pocket costs for patients taking orally administered anticancer therapies and other outpatient prescription drugs. However, these measures may not be sufficient to control out-of-pocket costs because of remaining policy gaps, such as the lack of out-of-pocket spending limits on Medicare Part D and the growing reliance on coinsurance rather than copayments for calculating beneficiary cost sharing. This is critically important as inflation in drug prices continues to increase at a remarkable pace, placing seniors at financial risk. These underlying pricing dynamics must be addressed to ensure patients have access to the growing number of treatments offered through Part D plans.

For commercially insured patients, the out-of-pocket maximum provision may provide significant financial relief for patients facing a new cancer diagnosis and high spending. However, many patients now face high deductibles that may limit their access to treatments. Our review of the literature also suggests that the current out-of-pocket spending limits may be unaffordable in relation to the amount of liquid assets available to many families.46 However, in the context of the potential out-of-pocket cost of cancer treatment without a maximum, it should be viewed as indisputable progress in limiting financial toxicity associated with cancer.

As of the writing of this article, the fate of the ACA and future health care reform efforts are unknown. We remain hopeful that efforts to repeal and replace the ACA will not reverse the progress that has been made for improving access to care for many patients. At the same time, we have highlighted some important gaps left by the ACA that could be targeted by replacement plans. Addressing these issues may help to increase access to care and affordability for patients with cancer and without.

**ACKNOWLEDGMENT**

The authors thank Dr. Joel F. Farley for helpful feedback on an earlier draft of this article.
REFERENCES


