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# The Affordable Care Act and income-based disparities in health care coverage and spending among nonelderly adults with cancer

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## Abstract

The Patient Protection and Affordable Care Act (ACA) significantly reduced uninsured individuals and improved financial protection; however, escalating costs of cancer treatment has led to substantial out-of-pocket expenses, causing severe financial and mental health distress for individuals with cancer. Mixed evidence on the ACA's ongoing impact highlights the necessity of assessing health-spending changes across income groups for informed policy interventions. In our nationally representative survey evaluating the early- and long-term effects of the ACA on nonelderly adult patients with cancer, we categorized individuals-based income subgroups defined by the ACA for eligibility. We found that ACA implementation increased insurance coverage, which was particularly evident after 2 years of implementation. Early post-ACA (within two years of implementation), there were declines in out-of-pocket spending for the lowest and low-income groups by 26.52% and 38.31%, respectively, persisting long-term only for the lowest-income group. High-income groups experienced continuously increased out-of-pocket and premium spending by 25.39% and 34.28%, respectively, with a notable 122% increase in the risk of high-burden spending. This study provides robust evidence of income-based disparities in financial burden for cancer care, emphasizing the need for health care policies promoting equitable care and addressing spending disparities across income brackets.

**Key words:** Affordable Care Act; health equity; health care costs; cancer; Medical Expenditure Panel Survey data.

## Introduction

Cancer is a major public health problem globally and is the second-leading cause of death in the United States.[1] An estimated 1,806,590 new cancer cases were diagnosed in 2020 alone and 606,520 people were estimated to die from the disease.[2] Cancer care expenses are on a consistent upward trajectory in the United States, projected to surge by over 30% from 2015 to 2030, reaching approximately $246 billion, creating a significant burden for both health care payers and patients.[3] As treatment costs rise and cost-sharing increases, families face substantial financial burdens, posing challenges in managing out-of-pocket expenses within the cancer care system, with many families ill-equipped to handle these escalating costs.[4,5] This financial strain has given rise to the concept of financial toxicity. Financial toxicity refers to the detrimental effect of a cancer diagnosis on a patient's financial well-being, stemming from both direct and indirect costs associated with their care.[6] The consequences of financial toxicity are extensive, spanning from bankruptcy to diminished quality of life to exacerbated disease outcomes and is identified as a distinct consequence of cancer treatment.[6-8]

The affordability of health care in the United States was improved through the Patient Protection and Affordable Care Act (ACA).[9,10] The ACA expanded health insurance coverage through no-cost and subsidized coverage to low- and middle-income families, improving financial protection.[10] Although increasing the number of insured individuals is an important measure of the ACA effect, diseases like cancer can cause significant out-of-pocket spending and, consequently, financial burden.[11] Few studies have assessed the effect of the ACA on health care access among populations with cancer. These studies have almost unanimously reported improved coverage gains,[4,12-16] but reports on financial burden have been inconsistent.[12,13,17,18] For instance, Hong et al[17] reported lower out-of-pocket expenses but increased premium payments, concluding that there was no significant impact of the ACA on perceived financial burden. Segel et al[4] reported significant declines in uninsurance rates but no significant change in financial burden. Su et al[16] reported reduced odds of financial barriers post-ACA using response data from cancer survivors.

Our study enhances the current understanding of the financial burden of cancer care by using recent data and a more informative approach. By stratifying patients into key subgroups based on the ACA statutory thresholds that define eligibility for Medicaid or subsidized insurance, and therefore income brackets, we were able to compare health care spending among these subgroups and assess their risk of financial

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burden.[19] This approach allows for a more nuanced analysis of how different patient subgroups are affected, providing valuable insights for future policy changes, such as expanded governmental and private insurance price negotiation and further evaluation of alternate payment models.[6] The primary objective of our study was thus to quantify the early and long-term impacts of the ACA on health care spending among nonelderly patients with cancer in the United States and, secondarily, to identify patient subpopulations at high risk of financial burden based on their income.

## Data and methods

### Study design and data source

We performed a retrospective cross-sectional study using the Medical Expenditure Panel Survey (MEPS) data, from the years 2011 through 2020. The MEPS is a nationally representative survey from the Agency for Healthcare Research and Quality (AHRQ).[20] The survey uses an overlapping panel design, where every year a new panel is enrolled and completes 5 rounds of interviews covering 2 full calendar years.[21] Due to the overlapping panel design of the MEPS, individuals may be present in the data from 2 consecutive annual files.[21] Each occurrence is treated as a distinct observation and the issue of multiple measurements is appropriately accounted for by the stratum and primary sampling unit design variables.[22] The MEPS collects information on demographics, family income, health status, health care use (eg, outpatient visits and hospitalizations), payments made by insurance, and participant out-of-pocket spending (deductibles, copayments, and coinsurance). The MEPS provides survey weights for extrapolating the civilian, noninstitutionalized US population and their families.[21] The MEPS data are de-identified and publicly available. Hence, this study was considered exempt by the University of Houston Institutional Review Board. Our study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.[23]

### Study population

We used the MEPS to identify nonelderly adults (aged 18–64 years) with cancer as the primary diagnosis from 2011 to 2020. We excluded nonmelanoma skin cancer due to the distinct course of the disease compared with other malignant cancers.[4,13,24] We also excluded those aged ≥65 years because the ACA was primarily focused on working-age adults.[25] To reduce the degree of misclassification and identify patients with current cancer, we mapped self-reports of cancer in the MEPS household components file to the International Classification of Diseases (ICD), Ninth and Tenth Edition, codes–based diagnoses in the MEPS medical conditions file (Tables S1 and S2). We then used the MEPS event files to identify if these patients had at least 1 cancer-related visit or prescription drug fill that year.[4] We stratified patients into 4 income groups in accordance with statutory thresholds set by the ACA to define Medicaid eligibility and subsidized insurance.[19] These groups were defined as follows:

- Lowest income: those with family incomes of ≤138% of the Federal Poverty Level (FPL); this group is eligible for Medicaid in states that expanded the program under the ACA.
- Low income: 139%–250% of the FPL; these groups, under the ACA, are eligible for subsidized premiums and reduced cost sharing.
- Middle income: 251%–400% of the FPL, who generally qualify for premium subsidies but not for reduced cost sharing.
- Higher income: >400% of the FPL, this group under the ACA is not eligible for subsidies.

We categorized individuals into these income groups using the FPL for family size in the relevant year and the family income variable provided in the MEPS.[26]

### Main exposure

The primary exposure was the ACA. The ACA's individual mandate and the main insurance expansion programs went into effect on January 1, 2014.[25] We structured our analysis around distinct periods relative to this date: the period before the expansion (full calendar years 2011 to 2013), the early implementation phase of the ACA (full calendar years 2014 to 2015), and a longer-term period (full calendar years 2016 to 2020).[19,27] For simplicity, we referred to these periods as the pre-ACA, early post-ACA, and the continued post-ACA eras, respectively. The continued post-ACA era allowed us to examine the continued effect of the ACA because some implementations, such as Marketplace enrollment, were not fully implemented until then[19,25]. It also coincides with the growing era of newer but more expensive cancer therapeutics, which can influence out-of-pocket payments.[28]

### Explanatory variables

Characteristics that might be associated with benefits obtained through the ACA and health care spending were considered as potential confounders and included respondents' age, sex, race/ethnicity, marital status, census region, educational level, employment status, family size, firm size for employed patients, self-reported physical and mental health status, and comorbidity burden, defined using the Agency for Healthcare Research and Quality (AHRQ) Elixhauser comorbidity index.[29]

### Health care spending (outcome) variables

Outcome variables were health insurance gains, health care spending, and financial burden. We defined health insurance gains as the total months with Medicaid and private insurance in a calendar year. The MEPS provides month-to-month reports of insurance coverage for each insurer, along with cases of complementary or supplemental coverage resulting in multiple insurers. We therefore aggregated monthly insurance status or supplemental coverage for each respondent in each calendar year. To quantify health care expenses, we used variables in the MEPS Household Component files (MEPS-HC) to create 3 spending variables. First, the individual's out-of-pocket expenses for the calendar year; this is the sum of total expenditures made for all possible health care encounters, such as inpatient stays, outpatient and emergency services, physician fees, prescription drugs, and home health visits. Second, the annual health insurance premium paid by patients' families was identified using the MEPS person round plan file, and last, the total sum of payments (out-of-pocket and premium expenditures).[19]

To assess the likelihood of financial burden and to quantify it, we used the MEPS family definition, explained as cohabiting individuals linked by blood, marriage, adoption, foster care, or self-identification as a family unit, as done in previous studies.[19,30,31] We studied the percentage of patients whose out-of-pocket spending exceeds 5% and 10% of family income.[19] The former is used for the bottommost 2-income groups as an accepted measure of affordability for low-income populations.[19,32,33] We also studied premium spending exceeding 9.5% of family income.[19] This is premised on the ACA's provision that allows individuals whose employer-offered insurance premium is more than 9.5% of family income to relinquish the employer-based option in favor of an exchange plan.[19,34] We then considered high-burden total health spending, also reported as catastrophic health expenditures (CHEs), as defined in previous studies as exceeding 19.5% (10% out-of-pocket plus 9.5% premium spending) of family income.[19,27]

### Statistical analysis

We used survey weights provided by the MEPS to generate nationally representative estimates and averaged weights to account for pooled years. For descriptive analyses, we examined changes in patient sociodemographic characteristics, socioeconomic indicators, insurance type and status, and health status pre- and post-ACA periods using analysis of variance (ANOVA) for continuous variables and chi-square tests for categorical variables. Insurance status encompassed patients' primary insurance coverage for the entire calendar year (private, public, uninsured). For insured individuals, we examined their specific source of insurance at the end of the calendar year, which included Medicaid, private insurance obtained through a group or employer, or private insurance acquired through a federally facilitated, state-based, or state partnership exchange/Marketplace. For our multivariable analyses, we adjusted for a priori–identified potential confounders (sociodemographic characteristics, socioeconomic indicators, and health status) and MEPS calendar years from before to after ACA implementation. We first compared outcomes across patient income groups and over the ACA implementation timeframe. For continuous outcomes (insurance gains and health care spending), we initially assessed their distributions for linearity, skewness, and zero inflation (Figure S1). We examined associations between ACA implementation and health care spending using two-part models consisting of a probit model that estimated the probability of using health care services (with spending) in the given period and a multivariable generalized linear model (GLM) with a gamma distribution and log link that estimated the outcome conditional on having incurred positive costs/insurance coverage. We examined associations between the ACA and financial burden (ie, whether respondents exceeded spending thresholds) using multivariable logistic regression models and bootstrapped estimates (1,000 iterations). The prognostic variables in the logistic models were time (ACA era), income group, and interaction between time and income group, in addition to covariates.[19] We confirmed that there was no correlation between this time variable and the MEPS calendar years, as assessed using the correlation matrix (<0.8). To further understand the effect of the ACA on populations with cancer, we additionally conducted similar analyses in non-cancer populations. For all analyses, we used two-tailed tests and set the alpha level at .05. SAS version 9.4 (SAS Institute, Cary, NC) was used for cohort building and descriptive measures. STATA version 17.0 (StataCorp LLC, College Station, TX) was used for inferential analysis. All expenditures were adjusted for inflation to 2020 US dollars using the medical component of the Consumer Price Index.[35]

### Sensitivity analyses

We conducted several sensitivity analyses. Firstly, we additionally adjusted for 4 measures of resource use in both linear and logistic regression models: outpatient and emergency visits, inpatient admissions, and prescription fills.[19] This was to determine whether possible reductions in spending in the post-ACA period were due to decreased use of health care services[19]. This was conducted for the overall study population and each income group. Secondly, we conducted a placebo analysis to identify potential secular trends in the pre-ACA era.[19] In these analyses, we compared spending in 2011 (pre-ACA period) with that in 2013 (early post-ACA period) and 2014 (long-term post-ACA period). Thirdly, instead of the MEPS definition, we used the Current Population Survey (CPS) family definition, explained as individuals living together and related by birth, marriage, or adoption.[27] Fourthly, we used alternate regression models to estimate changes in health care spending: a non-zero inflated GLM model and a linear regression to the logarithm of the continuous outcomes.[19] Additionally, we excluded patients aged 19 to 25 years in the analyses.[10] This is because these young adults may have gained insurance in 2010 under the ACA's Dependent Coverage Provision, which allowed them to use their parents' health insurance.[13] Lastly, we excluded respondents sampled in 2020 because the COVID-19 pandemic might have influenced insurance coverage and spending.

## Results

### Characteristics of the study population

We identified a total of 7,654 MEPS respondents aged between 18 and 64 years who reported having cancer in a given year during the period from 2011 to 2020. These respondents were from 7,638 households. After applying survey weights, this sample represented a total of 16,281,147 nonelderly patients with cancer in the United States, comprising 34.98% males and 65.02% females, with a mean (SD) age of 49.25 (0.31) years and a median family size of 1.58 (IQR: 0.86–2.47).

Modest changes in respondents' sociodemographic and health-related characteristics were observed pre- to post-ACA (Table 1 and Table S3). Having public insurance increased from 13.23% to 16.59% early post-ACA and to 19.55% long-term post-ACA, while percentages of noninsured patients decreased in a similar fashion. The increase in Medicaid coverage was very small early post-ACA (0.76%) but increased to a larger extent (4.43%) long-term post-ACA. The proportion of persons on exchange plans increased only modestly post-ACA (4.33%–4.60% early to long-term post-ACA, respectively). Median family income increased pre- to post-ACA eras, even after adjusting for inflation ($63,174–$79,932). The quality of self-reported mental health decreased steadily pre- to post-ACA (excellent health: 50.51% to 45.73%).

**Table 1.** Distribution of key characteristics of the study population: nonelderly (18–64 years) patients with cancer by income categories.

| Characteristics | MEPS sample population[a] (%) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Lowest-income group (0%-138% of FPL) | | | Low-income group (139%-250% of FPL) | | | Middle-income group (251%-400% of FPL) | | | Higher-income group (>400% of FPL) | | |
| | Pre-ACA ($n = 583$) | Early post-ACA ($n = 342$) | Long-term post-ACA ($n = 689$) | Pre-ACA ($n = 362$) | Early post-ACA ($n = 215$) | Long-term post-ACA ($n = 447$) | Pre-ACA ($n = 455$) | Early post-ACA ($n = 250$) | Long-term post-ACA ($n = 524$) | Pre-ACA ($n = 1,285$) | Early post-ACA ($n = 741$) | Long-term post-ACA ($n = 1,761$) |
| US weighted population, *n* | 1,412,368 | 806,286 | 1,294,164 | 51,319 | 22,110 | 17,973 | 1,194,279 | 582,290 | 969,689 | 3,466,638 | 2,078,933 | 4,385,098 |
| Age, mean (SD), y | 48.14 (0.63) | 49.61 (0.89) | 49.82 (0.50) | 43.17 (4.51) | 43.22 (3.42) | 45.92 (5.54) | 47.66 (0.52) | 48.85 (0.95) | 48.79 (0.75) | 49.56 (0.44) | 49.32 (0.51) | 49.80 (0.31) |
| Female | 71.12 | 68.68 | 68.61 | 87.78 | 42.84 | 72.28 | 70.03 | 63.55 | 69.49 | 62.25 | 62.36 | 63.06 |
| Race/ethnicity | | | | | | | | | | | | |
| White, non-Hispanic | 68.01 | 65.05 | 65.96 | 82.77 | 78.15 | 51.71 | 74.49 | 73.19 | 72.55 | 83.43 | 82.01 | 82.35 |
| Black, non-Hispanic | 13.94 | 15.47 | 14.17 | 3.32 | 3.22 | 17.35 | 10.95 | 10.08 | 13.81 | 5.71 | 5.53 | 5.95 |
| Asian, non-Hispanic | 2.16 | 0.89 | 0.90 | 1.01 | 1.01 | 24.93 | 3.02 | 1.65 | 1.88 | 2.49 | 3.47 | 2.63 |
| Hispanic | 12.25 | 13.10 | 13.54 | 8.54 | 14.32 | 6.02 | 10.25 | 12.91 | 9.32 | 6.81 | 7.44 | 7.24 |
| Others, non-Hispanic | 3.64 | 5.48 | 5.43 | 5.37 | 7.53 | 3.00 | 1.28 | 2.17 | 2.44 | 1.56 | 1.55 | 1.83 |
| Marital status | | | | | | | | | | | | |
| Married | 79.29 | 73.29 | 72.80 | 29.75 | 42.84 | 6.02[b] | 51.87 | 50.68 | 37.26[b] | 79.29 | 73.29 | 72.80[b] |
| Widowed/separated/ divorced | 10.20 | 112.84 | 14.80 | 60.34 | 15.67 | 87.84 | 27.56 | 31.09 | 37.46 | 10.20 | 12.84 | 14.80 |
| Never married | 10.51 | 13.87 | 12.40 | 9.92 | 41.49 | 6.14 | 20.57 | 18.23 | 25.28 | 10.51 | 13.87 | 12.40 |
| Mean family income median (IQR),[c] $ | 14,190 (8,584-22,028) | 9,061 (8,335-9,786) | 14,690 (8,862-22,674)[b] | 30,006 (29,994-30,062) | 30,000 (30,000-30,000) | 30,000 (30,000-30,151)[b] | 41,999 (35,954-48,736) | 43,002 (37,896-49,956) | 41,324 (36,510-48,365)[b] | 101,972 (75,597-145,992) | 104,306 (77,897-143,109) | 112,003 (80,910-164,365)[b] |
| Employed | 42.62 | 33.68 | 36.99[b] | 84.98 | 85.26 | 65.47 | 69.62 | 71.39 | 73.29 | 79.52 | 79.07 | 81.50 |
| Region | | | | | | | | | | | | |
| Northeast | 17.33 | 15.16 | 14.68 | 25.87 | 5.89 | 0.00 | 15.84 | 11.59 | 17.76 | 18.89 | 22.24 | 20.74 |
| Midwest | 23.24 | 22.36 | 20.34 | 5.68 | 0.00 | 25.77 | 23.48 | 23.02 | 21.39 | 20.94 | 20.96 | 22.92 |
| South | 37.77 | 43.05 | 44.21 | 57.10 | 82.62 | 36.53 | 41.26 | 46.16 | 39.46 | 37.35 | 29.72 | 31.25 |
| West | 21.66 | 19.43 | 20.77 | 11.35 | 11.49 | 37.70 | 19.42 | 19.23 | 21.39 | 22.82 | 27.08 | 25.09 |
| Insurance status[d] | | | | | | | | | | | | |
| Public | 42.35 | 53.05 | 63.53[b] | 0.64 | 26.23 | 34.44 | 11.31 | 14.57 | 25.75[b] | 2.21 | 2.92 | 5.13[b] |
| Private | 36.29 | 35.48 | 29.44 | 92.36 | 73.77 | 59.42 | 78.87 | 77.00 | 69.77 | 93.29 | 93.27 | 92.79 |
| Not insured | 21.40 | 11.47 | 7.03 | 7.00 | 0.00 | 6.14 | 9.82 | 8.44 | 4.48 | 4.50 | 3.81 | 0.70 |
| Self-reported physical health status | | | | | | | | | | | | |
| Excellent | 18.13 | 15.18 | 16.52 | 16.87 | 16.44 | 18.22 | 22.28 | 24.77 | 21.11 | 38.02 | 40.40 | 34.67[b] |
| Good/better | 57.44 | 56.20 | 53.55 | 79.64 | 67.65 | 75.62 | 66.97 | 63.96 | 66.40 | 55.84 | 53.86 | 61.57 |
| Fair/poor | 24.42 | 28.62 | 29.93 | 3.75 | 11.26 | 6.22 | 10.75 | 11.27 | 12.49 | 6.14 | 5.73 | 3.76 |

Abbreviations: ACA, Patient Protection and Affordable Care Act; FPL, Federal Poverty Level; MEPS, Medical Expenditure Panel Survey.
The pre-ACA period represents calendar years 2011 to 2013, the early post-ACA period represents calendar years 2014 to 2015, and the long-term post-ACA era represents calendar years 2016 to 2020. Race/ethnicity: Others, non-Hispanic includes non-Hispanic Asians, American Indian or Alaska Natives, Native Hawaiian or Pacific Islanders, and multiple races.
[a]Percentages are weighted to provide population estimates. Cancer diagnosis was identified using the International Classification of Diseases code in the MEPS Medical Conditions file. It represents diagnosis based on health care utilization in the sample year. Individuals aged between 18 to 64 years were included.
[b]Statistical significance at a 5% confidence level ($P < .05$) for the difference between ACA groups (pre- and post-ACA periods) in the same income group using analysis of variance (ANOVA) for continuous variables and chi-square test for categorical variables.
[c]Income is provided in 2020 US dollars using the medical component of the Consumer Price Index.
[d]Indicates having any private coverage, including TRICARE and the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) at any point during the calendar year, having only public insurance excluding TRICARE/CHAMPVA throughout the year, or being uninsured for the entire calendar year. Private insurance included commercial insurance coverage obtained through an employer, on the ACA Marketplaces, or through other sources.

### Changes in health care coverage and spending

Medicaid coverage increased long-term post-ACA in both the full sample by 7.74% (95% CI: 0.81%–4.67%; $P = .03$) and across all income groups, except for the high-income populations (lowest-income: 12.62%; 95% CI: 5.07%–20.18%; $P = .001$; low-income: 9.87%; 95% CI: 9.87%–13.01%; $P = .01$; and middle-income: 17.08%; 95% CI: 0.78%–33.40%; $P = .04$) (Table 2). Coverage through private insurance was significant in both post-ACA eras and was largely influenced by increased private coverage for high-income patients (early post-ACA: 13.87%; 95% CI: 10.73%–17.00%; $P < .0001$; long-term post-ACA: 14.82%; 95% CI: 11.65%–17.98%; $P < .0001$).

The mean out-of-pocket payment for the full sample was $2,003.54 and increased steadily from the lowest-income group ($1,479.12) to the highest-income group ($2,299.91). Early post-ACA era, out-of-pocket expenses decreased only for the lowest-income (−26.52%; 95% CI: −42.40% to −6.27%; $P = .01$) and low-income groups early post-ACA era (−38.31%; 95% CI: −55.48% to −14.52%; $P = .004$). Long-term post-ACA, the reduction persisted for the lowest-income group only and to a greater extent (−36.73%; 95% CI: −51.59% to −17.32%; $P = .001$), while out-of-pocket expenses increased for high-income groups (25.39%; 95% CI: 8.26%–45.23%; $P = .003$). Annual premium payments were lowest among the bottom-2 income groups and highest among the top-2 income groups (43.45% higher in the highest-income group compared to the lowest). Total health care spending decreased progressively for the lowest-income groups in both post-ACA eras (early: −23.73%; 95% CI: −38.77% to −4.97%; $P = .02$; long-term: −31.29%; 95% CI: −46.37% to −11.96%; $P = .003$), while it increased progressively for the high-income groups in both eras (early: 9.19%; 95% CI: 8.38%–9.99%; $P < .0001$; long-term: 23.95%; 95% CI: 20.92%–27.04%; $P < .0001$).

### Income-related differences in health care spending

For out-of-pocket expenses (Table 3), the lowest- and low-income groups combined had 34.82% higher odds (adjusted odds ratio [aOR]: 1.35; 95% CI: 1.04–1.75; $P = .03$) of expenses exceeding 5% of their income in the early- vs pre-ACA era. High-income groups had 85% (aOR: 1.85; 95% CI: 1.18–2.91; $P = 0.01$) higher odds of expenses exceeding 10% but only in the long-term post-ACA era. For premiums, spending increased by 53.51% early pre-ACA (aOR: 1.54; 95% CI: 1.00–2.36; $P = .05$) and by 77.22% long-term post-ACA (aOR: 1.77; 95% CI: 1.20–2.62; $P = .004$) compared with the pre-ACA era in high-income groups. The likelihood of CHEs (Figure 1, Table 3) increased by 73.60% in the early post-ACA (aOR: 1.74; 95% CI: 1.06–2.91; $P = .04$) vs the pre-ACA era and by 121.95% (aOR: 2.22; 95% CI: 1.30–3.78; $P = .003$) in the long-term post-ACA era vs. the pre-ACA era.

### Findings from supporting analyses

Adjusting for health care utilization (Tables S4 and S5) did not qualitatively change our findings. Using the CPS family definition (Tables S6 and S7) did not also change our findings qualitatively, except that the ACA was protective of only the lowest-income group populations and high-income patients experienced increased spending in the early post-ACA era (premium spending: 15.76%; 95% CI: 2.89% to 30.23%; $P = .02$; CHE likelihood: aOR, 1.74; 95% CI: 1.06–2.91; $P < .0001$). Excluding patients aged 19–25 years (Tables S8 and S9), respondents sampled in 2020 (Tables S10 and S11), and retaining patients with zero expenditures using GLM and linear regression (Tables S12 and S13) did not change our findings qualitatively. Placebo tests (Tables S14 and S15) showed changes in spending only in the placebo long-term post-ACA era (2013). Patients with cancer had higher unadjusted health care spending compared with those without cancer in each calendar year (Figure S2). In the adjusted analyses assessing changes in spending and financial burden among the sample without cancer (Tables S16 and S17), the lowest-income groups experienced lower total spending in the early and long-term post-ACA eras (early: −46.39%; 95% CI: −88.70% to −3.23%; $P = .02$; long-term post-ACA: −32.67%; 95% CI: −49.74% to −15.21%; $P = .001$). Total spending and the likelihood of CHEs (early: aOR, 1.31; 95% CI: 1.05–1.64; $P = .02$; long-term: aOR, 1.74; 95% CI: 1.40–2.15; $P < .0001$) for high-income patients were higher in both eras. However, the magnitude of the decreased spending for lower-income groups and increased spending for high-income groups were lower compared with the sample with cancer.

## Discussion

In this nationally representative, cross-sectional study of 7,654 nonelderly adult patients with cancer, we found that the implementation of the ACA in January 2014 was associated with decreased out-of-pocket spending among low-income US adults with cancer who were eligible for the policy's Medicaid expansion and Marketplace subsidies within the first 2 years of its implementation. However, this decreased out-of-pocket spending was sustained only for those eligible for Medicaid expansion (<138% of FPL) beyond 2 years post-implementation. This group also exhibited increased public insurance coverage and sustained decreased out-of-pocket expenses for up to 7 years post-implementation. Conversely, high-income patients experienced higher expenses compared with the pre-ACA era, particularly after 2 years post-ACA, with out-of-pocket costs and premium spending increasing by 25.39% and 34.28%, respectively. Furthermore, high-income patients were at a 122% higher risk of financial burden. These findings underscore the relevance of the ACA in improving health care access and reducing spending for lower-income individuals but also highlight a potential risk of financial toxicity for high-income individuals with cancer.

Consistent with findings from previous studies, we noted only modest improvements in insurance gains for lower-income patients, particularly during the early post-ACA era.[4,36-39] This observation may be attributed to the delayed impacts of the ACA provision.[4] Additionally, our inclusion of both "expansion states" (ie, states that have implemented the ACA Medicaid expansion or equivalent program) and "non-expansion states" (states that have not) could have contributed to these findings.[11] As of January 2020, 35 states and the District of Columbia had expanded Medicaid, while 15 states had not.[40,41] The coverage gap experienced by individuals in non-expansion states who may not qualify for Medicaid or subsidies may therefore account for a smaller coverage gain in the overall population, as observed. We were unable to account for this in our study. We did not observe insurance gain even for low-income groups in the early

**Table 2.** Pre- to post-ACA changes in mean coverage, out-of-pocket, and premium spending among patients aged 18 to 64 years with cancer.

| Income category (% of FPL) | Mean months of coverage/spending, US dollars | | | Change from pre-ACA to post-ACA periods[a] | | | |
|---|---|---|---|---|---|---|---|
| | Pre-ACA period | Estimated change in coverage/spending, early post-ACA period | Estimated change in coverage/spending, long-term post-ACA period | Pre-ACA to early post-ACA period | | Pre-ACA to long-term post-ACA period | |
| | | | | Adjusted change in percentage (95% CI) | *P* value[b] | Adjusted change in percentage (95% CI) | *P* value[b] |
| Months of Medicaid | | | | | | | |
| All patients | 1.43 | 1.60 | 2.92 | 2.46 (−5.54 to 10.47) | .60 | 7.74 (0.81 to 4.67) | **.03** |
| Lowest-income patients | 6.63 | 2.01 | 4.06 | 3.09 (−5.6 to 11.8) | .49 | 12.62 (5.07 to 20.18) | **.001** |
| Low-income patients | 2.98 | 0.27 | 2.43 | 2.16 (−4.32 to 10.15) | .45 | 9.87 (3.21 to 13.01) | **.01** |
| Middle-income patients | 2.07 | 0.31 | 0.77 | 1.63 (−20.97 to 24.23) | .89 | 17.08 (0.75 to 33.40) | **.04** |
| High-income patients | 0.28 | −0.16 | −0.32 | −20.31 (−62.77 to 22.16) | .35 | −33.97 (−80.92 to 12.98) | .16 |
| Months of private coverage | | | | | | | |
| All patients | 8.85 | 0.11 | 0.41 | 11.15 (8.26 to 14.04) | **<.0001** | 14.16 (11.47 to 16.85) | **<.0001** |
| Lowest-income patients | 2.07 | 0.78 | 0.47 | 5.83 (−4.74 to 16.40) | .28 | 8.67 (−1.23 to 18.57) | .09 |
| Low-income patients | 6.11 | −0.36 | −1.40 | 6.87 (−3.45 to 18.76) | .15 | 7.60 (−0.33 to 19.83) | .08 |
| Middle-income patients | 8.48 | −0.51 | 0.04 | 5.20 (−2.55 to 12.96) | .19 | 12.14 (5.88 to 18.41) | **<.0001** |
| High-income patients | 10.68 | 2.01 | 2.95 | 13.87 (10.73 to 17.00) | **<.0001** | 14.82 (11.65 to 17.98) | **<.0001** |
| Out-of-pocket spending ($) | | | | | | | |
| All patients | 2,003.54 | −63.45 | −39.43 | −28.22 (−19.02 to −15.56) | .71 | 25.78 (6.89 to 48.01) | **.006** |
| Lowest-income patients | 1,479.12 | −303.49 | −504.49 | −26.52 (−42.40 to −6.27) | **.01** | −36.73 (−51.59 to −17.32) | **.001** |
| Low-income patients | 2,070.11 | −744.99 | −498.72 | −38.31 (−55.48 to −14.52) | **.004** | −8.77 (−34.30 to 2.39) | .58 |
| Middle-income patients | 2,282.63 | 450.59 | −155.14 | −6.20 (−23.81 to 48.03) | .72 | −2.05 (−26.91 to 31.27) | .88 |
| High-income patients | 2,299.91 | 98.92 | 281.65 | 10.21 (6.67 to 13.42) | **.02** | 25.39 (8.26 to 45.23) | **.003** |
| Premium spending ($) | | | | | | | |
| All patients | 3,856.92 | 4.42 | 681.60 | −0.65 (−11.94 to 12.09) | .92 | 26.06 (13.28 to 40.28) | **<.0001** |
| Lowest-income patients | 2,941.65 | 168.24 | −66.59 | −15.23 (−40.67 to 21.10) | .36 | −7.86 (−35.71 to 32.02) | .66 |
| Low-income patients | 3,141.19 | −189.14 | −556.48 | −9.23 (−26.84 to 34.07) | .95 | 28.85 (−4.76 to 74.34) | .10 |
| Middle-income patients | 3,040.96 | −129.24 | −234.02 | 12.26 (−15.75 to 49.58) | .43 | 19.38 (−7.20 to 53.58) | .17 |
| High-income patients | 4,219.92 | −5.95 | 547.33 | 3.21 (−8.13 to 15.95) | .59 | 34.28 (19.63 to 50.73) | **<.0001** |
| Out-of-pocket and premium spending ($) | | | | | | | |
| All patients | 9,746.82 | 66.31 | 755.18 | −2.80 (−11.60 to 6.43) | .56 | 3.69 (−4.97 to 13.13) | .42 |
| Lowest-income patients | 4,005.74 | −263.01 | −543.48 | −23.73 (−38.77 to −4.97) | **.02** | −31.29 (−46.37 to −11.96) | **.003** |
| Low-income patients | 7,411.83 | −939.67 | −1,001.85 | −6.29 (−23.17 to 35.75) | .25 | −3.68 (−20.57 to 16.78) | .70 |
| Middle-income patients | 10,688.00 | −176.00 | −1,367.06 | −2.95 (−24.60 to 24.92) | .12 | −11.77 (−27.42 to 7.26) | .21 |
| High-income patients | 12,983.00 | 419.00 | 1,908.00 | 9.19 (8.38 to 9.99) | **<.0001** | 23.95 (20.92 to 27.04) | **<.0001** |

Abbreviations: ACA, Patient Protection and Affordable Care Act; FPL, Federal Poverty Level.
Estimates were performed at the individual level for out-of-pocket sending and at the household level for premium contributions. Expenditures were adjusted for inflation to 2020 dollars using the medical component of the Consumer Price Index. Mean out-of-pocket plus premium spending is the sum of the amount paid and the total premium contribution made by families; since all spending is calculated from separate multivariable models, the mean combined out-of-pocket and premium spending may not equal the sum of individual expenditures.
[a]Adjusted for age, sex, race/ethnicity, marital status, family size, region, firm size, employment status, self-reported physical and mental health status, and Elixhauser comorbidity index score.
[b]*P* values in bold denote statistical significance at alpha = .05 compared with pre-ACA.

**Table 3.** Prevalence and risks of financial burden among patients with cancer aged to 18 to 64 years in the pre- and post-ACA periods.

| Income category (% of FPL) | Exceeding threshold, % | | | Change from pre-ACA to post-ACA periods[a] | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | Early post-ACA change | | | Long-term post-ACA change | | |
| | Pre-ACA period | Early post-ACA period | Sustained post-ACA period | Adjusted change (%) | Adjusted OR (95% CI) | *P* value[b] | Adjusted change (%) | Adjusted OR (95% CI) | *P* value[b] |
| Out-of-pocket spending >5% of family income | | | | | | | | | |
| All patients | 42.01 | 48.06 | 40.25 | 34.82 | 1.35 (1.04 to 1.75) | **.03** | 13.10 | 1.13 (0.91 to 1.40) | .29 |
| Lowest-income patients | 22.57 | 26.54 | 24.33 | 26.64 | 1.27 (0.79 to 2.02) | .32 | 3.87 | 1.04 (0.66 to 1.63) | .85 |
| Low-income patients | 13.14 | 14.41 | 14.34 | 73.62 | 1.74 (0.98 to 3.09) | .06 | 46.62 | 1.47 (0.84 to 2.57) | .18 |
| Out-of-pocket spending >10% of family income | | | | | | | | | |
| All patients | 19.09 | 22.13 | 20.44 | 18.29 | 1.18 (0.87 to 1.60) | .27 | 35.04 | 1.35 (0.99 to 1.83) | .05 |
| Lowest-income patients | 33.14 | 33.53 | 32.37 | −5.68 | 0.94 (0.59 to 1.51) | .81 | 4.10 | 1.04 (0.64 to 1.69) | .87 |
| Low-income patients | 19.81 | 16.10 | 18.71 | −21.28 | 0.79 (0.41 to 1.49) | .46 | 44.12 | 1.44 (0.78 to 2.67) | .24 |
| Middle-income patients | 21.00 | 24.81 | 16.91 | 30.67 | 1.31 (0.71 to 2.39) | .35 | −2.43 | 0.98 (0.53 to 1.79) | .94 |
| High-income patients | 26.04 | 25.56 | 32.01 | 30.25 | 1.30 (0.80 to 2.13) | .29 | 85.00 | 1.85 (1.18 to 2.91) | **.01** |
| Premium spending >9.5% of family income | | | | | | | | | |
| All patients | 11.38 | 13.23 | 14.27 | 18.28 | 1.18 (0.86 to 1.63) | .30 | 35.64 | 1.35 (1.01 to 1.82) | **.04** |
| Lowest-income patients | 18.89 | 18.71 | 15.06 | −21.49 | 0.79 (0.40 to 1.54) | .48 | −4.02 | 0.96 (0.49 to 1.88) | .91 |
| Low-income patients | 17.25 | 14.06 | 11.86 | 11.92 | 1.20 (0.56 to 2.24) | .75 | 7.00 | 1.07 (0.51 to 2.27) | .86 |
| Middle-income patients | 27.94 | 25.62 | 24.46 | 19.53 | 1.20 (0.67 to 2.13) | .54 | 47.27 | 1.47 (0.82 to 2.65) | .20 |
| High-income patients | 35.92 | 41.60 | 48.62 | 53.51 | 1.54 (1.00 to 2.36) | **.05** | 77.22 | 1.77 (1.20 to 2.62) | **.004** |
| Out-of-pocket plus premium spending >19.5% of family income (CHEs) | | | | | | | | | |
| All patients | 14.63 | 15.68 | 15.60 | 17.34 | 1.17 (0.88 to 1.56) | .27 | 24.88 | 1.25 (0.96 to 1.62) | .09 |
| Lowest-income patients | 32.09 | 29.34 | 29.07 | −18.40 | 0.82 (0.49 to 1.37) | .44 | −3.51 | 0.97 (0.57 to 1.64) | .90 |
| Low-income patients | 22.07 | 19.68 | 16.78 | −2.58 | 0.97 (0.51 to 1.85) | .94 | 7.49 | 1.08 (0.55 to 2.12) | .83 |
| Middle-income patients | 25.94 | 26.37 | 20.96 | 47.2 | 1.47 (0.74 to 2.92) | .27 | 2.09 | 1.02 (0.59 to 1.76) | .94 |
| High-income patients | 19.90 | 24.62 | 33.19 | 73.60 | 1.74 (1.06 to 2.91) | **.04** | 121.95 | 2.22 (1.30 to 3.78) | **.003** |

Abbreviations: ACA, Patient Protection and Affordable Care Act; CHE, catastrophic health expenditure; FPL, Federal Poverty Level; OR, odds ratio.
Individuals between 18 to 64 years were included.
[a]Adjusted for age, sex, race/ethnicity, marital status, family size, region, firm size, employment status, self-reported physical and mental health status, and Elixhauser comorbidity index score.
[b]*P* values in bold denote statistical significance at alpha = .05 compared with the pre-ACA era.

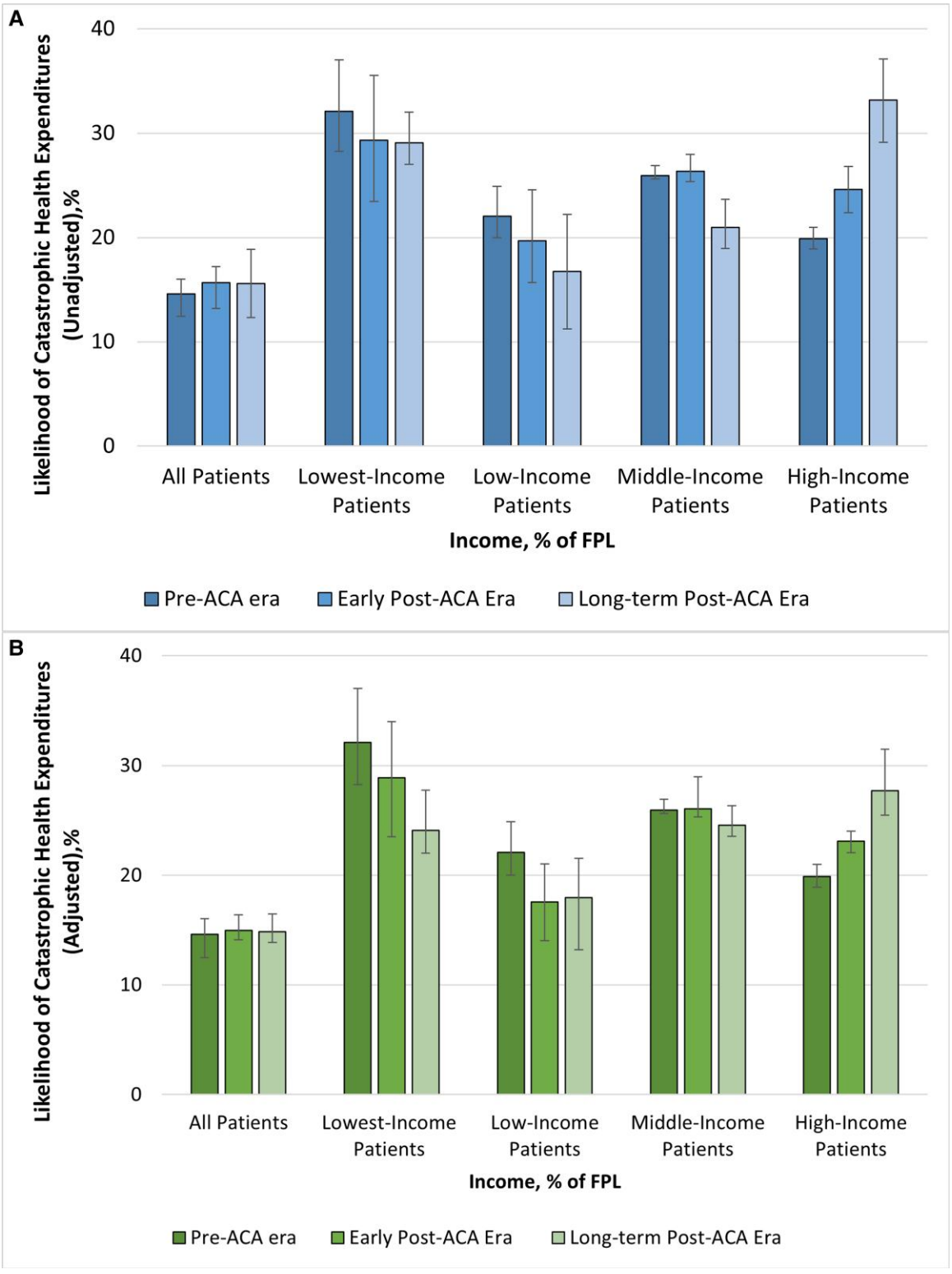


**Figure 1.** A and B: Likelihood of catastrophic health expenditures before and after implementation of the ACA. Error bars denote 95% CIs. A catastrophic health expenditure is defined as having combined out-of-pocket and premium spending exceeding 19.5% of total family income. The analyses were performed using individuals as the unit of analysis. The pre-ACA era includes pooled samples of years 2011 to 2013. The early post-ACA era includes pooled samples of years 2014 and 2015. The long-term ACA era includes pooled samples from 2016 to 2020. Income groups are defined based on stratification according to the FPL. The lowest-income patients are those earning ≤138% of the FPL; low-income patients are those earning between 139% and 250% of the FPL; middle-income patients are those earning between 251% and 400% of the FPL, and high-income patients are those earning ≥400% of the FPL. Income was estimated in 2020 US dollars. The blue bars show unadjusted differences, while the green bars show adjusted differences (adjusted for age, sex, race/ethnicity, marital status, family size, region, firm size, employment status, self-reported physical and mental health status, and Elixhauser comorbidity index score) with the pre-ACA era as the reference. $P < .05$ indicates statistical significance at alpha = .05. Abbreviations: ACA, Affordable Care Act; FPL, Federal Poverty Level.

post-ACA era ($P > .05$), similar to a report that evaluated 2-year post-ACA implementation,[4] but in our longer-term post-ACA era, there was a 4-month increase in coverage for patients earning <138% of the FPL, suggesting that the impacts of ACA provisions were delayed. This is supported by previous reports that about 28 million Americans remained uninsured during this era[42] and that 6.5% of all populations became newly insured after the ACA.[19] The middle-income patients experienced a modest increase in Medicaid coverage but a varied percentage increase in coverage (0.75%–33.40%). This group under the ACA provisions does not qualify for Medicaid coverage but may qualify for exemptions such as catastrophic plans[43] due to the high health care financial burden characteristic of cancer care.[43] As expected, private health insurance increased post-ACA, largely driven by middle- and high-income patients post-ACA. Middle-income patients experienced an increase in private coverage long-term post-ACA, suggesting increased enrollment in the health care Marketplace.[19]

We observed reduced out-of-pocket spending but no change in premium payments among low-income groups. This has been reported in cancer and non-cancer populations.[4,19,27] Medicaid is generally associated with minimal premiums or cost-sharing.[43] Premiums paid by high-income patients were higher post-ACA. This substantiates reports of an increase in family premiums over the years.[44] Middle-income patients generally had higher, but nonsignificant, odds of high-burden spending; this was observed in a previous study on patients with traumatic injury and can be attributed to higher copayments and deductibles associated with purchasing insurance in the Marketplace and other private insurance compared with Medicaid.[27] There is also evidence that this group may purchase less generous Marketplace plans and might have more employer-sponsored insurance, which is generally associated with underinsurance,[45] concealing the financial benefits associated with ACA-related coverages.[27] Similar to a study finding,[27] only a small fraction (4%) of the middle-income group reported having ACA Marketplace insurance coverage, and this subgroup had the highest proportion of uninsured patients. This modest transition from uninsured or underinsurance to the Marketplace may be associated with the non–statistically significant findings. While our findings indicated lower expenditures among lower-income patients, it is crucial to acknowledge the challenges that lower-income patients, particularly those covered by Medicaid, may face with access to care. These challenges include limited and restricted provider networks, which can hinder their ability to access timely and comprehensive health care services.[46] As such, the observed increase in insurance coverage and decreased health care spending may not translate to improved access to health care services among this group. The cost of cancer care has indeed increased significantly in the past decade, primarily driven by the introduction of newer therapies and the associated costs of their administration.[47,48] As such, in our secondary analyses, we controlled for health care utilization to better understand its impact on cancer care costs among patient subgroups. Controlling for health care utilization including prescription fills did not, however, alter our findings, although information on oncology drugs in the MEPS is limited and thus does not totally account for growing oncology drug costs. Private payers tend to reimburse at significantly higher rates for care, particularly with the introduction of new high-cost cancer therapies to the market.[47] Consequently, private payers inevitably pay much more both overall and relative to other payers, leading to higher out-of-pocket payments for patients.[47] Therefore, as reflected in our findings, it is expected that higher-income patients would incur more expenses than lower-income patients, particularly those who qualify for Medicaid. With regard to the health services received, outpatient expenditures have been identified as a significant driver of health care spending for patients with cancer, mainly due to the shift from inpatient to outpatient settings for cancer-related treatments.[48] However, due to the lack of detailed information in our database, we were unable to stratify expenses by specific health care services. Our findings from the analyses that showed differences in out-of-pocket spending for the pseudo–long-term post-ACA (2013) vs pre-ACA (2011) periods may be associated with secular trends or early expansions of Medicaid in some states. This observation aligns with a study that assessed the effects of the ACA on the general US population.[19] When we assessed key outcomes in the non-cancer population, we noticed that having cancer greatly impacts spending.

## Limitations

Our study has limitations. With respect to our key subject definition—that is, having cancer—MEPS does not offer comprehensive details on cancer type and treatments, and does not provide information on cancer prognosis (eg, cancer stage), which can affect health care expenses. Also, costs of cancer care may differ based on site, and we could not assess these differences across our patient strata because cancer site definition is not uniform in the MEPS across the years analyzed. Additionally, while we identified respondents with health care usage tied to a cancer diagnosis in a given year and with expenditures related to cancer, our study is still subject to prevalence bias. This is particularly relevant as cancer survivors who may not be under active treatment, may be included in the study population resulting in a different spending composition. Although we accounted for the study period in our analyses and conducted sensitivity analyses to assess the impact of COVID-19 on our findings, we acknowledge the limitations associated with analyzing data from the COVID-19 period, such as potential biases or confounding factors related to the pandemic's influence on health care utilization. The relatively small sample size of our study population affected the precision of our estimates and may impact our ability to identify small changes related to the ACA; however, we improved on this using bootstrapping. Our analyses were at individual and household levels, but we might have underestimated the financial burden in households with elderly people because the MEPS does not provide information on Medicare part B premiums.[19] Also, data on premiums in the MEPS are self-reported and may be subject to error. Furthermore, geographical variation in health care expenses might occur, and although our control for census region might reduce this, residual confounding is possible—for example, differences in ACA provisions between Medicaid expansion and non-expansion states, which may also affect our income-stratification thresholds. The information on MEPS respondents' states of residence is not available in the public-use MEPS data, which precludes analysis of whether the consequences of the ACA differed between Medicaid expansion and non-expansion states.

## Conclusion

Our nationally representative study focusing on patients with cancer shows a growing protective impact of the ACA on reducing expenses for the lowest-income groups. However, we observed limited effects on low- and middle-income individuals, while high-income patients continued to experience increased spending and higher risks of CHEs. Our supplemental findings show that health care costs among patients with cancer are much higher compared with those without the disease, supporting literature that those with cancer are 71% more likely than those without the disease to face financial setbacks, such as bills in collections or mortgage foreclosure.[49] Given these insights, our study suggests the potential importance of strategies and further exploring health care reforms to reduce financial burden among patients with cancer, particularly those tailored to address the challenges faced by high-risk populations like patients with cancer to alleviate the persistently higher costs they bear. These strategies could be implemented at multiple levels within the health care system, including provider, institutional, and health care payer levels. For example, a framework provided by the American Society for Clinical Oncology guides providers to consider factors such as clinical benefit, toxicity, net health benefit, and cost when making therapeutic decisions.[50] Additionally, the incorporation of financial toxicity screening into clinics and hospitals has been proposed as a means to identify and address financial challenges faced by patients.[6] At the payer level, strategies such as increasing competition among drug manufacturers, expanding government and private insurance price negotiation, and ongoing evaluation of alternate payment models have been suggested.[6] Furthermore, considering successful models observed in some countries, the implementation of a comprehensive health insurance program that transcends income and socioeconomic status may be beneficial for this population.[51]

Finally, as income-related disparities in healthcare spending and financial burden can vary by cancer site and prognosis, we encourage future studies to explore these nuances more comprehensively.

## Supplementary material

Supplementary material is available at *Health Affairs Scholar* online.

## Conflicts of interest

Please see ICMJE form(s) for author conflicts of interest. These have been provided as supplementary materials.

## Notes


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