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Financial burden of cancer care under the Affordable Care Act: Analysis of MEPS-Experiences with Cancer Survivorship 2011 and 2016

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Abstract

Purpose To examine whether the implementation of Affordable Care Act (ACA) reduced the financial burden associated with cancer care among non-elderly cancer survivors.

Methods Using data from the MEPS-Experiences with Cancer Survivorship Survey, we examined whether there was a difference in financial burden associated with cancer care between 2011 (pre-ACA) and 2016 (post-ACA). Two aspects of financial burden were considered: (1) self-reported financial burden, whether having financial difficulties associated with cancer care and (2) high-burden spending, whether total out-of-pocket (OOP) spending incurred in excess of 10% or 20% of family income. Generalized linear regression models were estimated to adjust the OOP expenditures (reported in 2016 US dollar).

Results Our sample included adults aged 18–64 with a confirmed diagnosis of any cancer in 2011 ($n = 655$) and in 2016 ($n = 490$). There was no apparent difference in the prevalence of cancer survivors reporting any financial hardship or being with high-burden spending between 2011 and 2016. The mean OOP decreased by $268 (95% CI, − 384 to − 152) after the ACA. However, we found that the mean premium payments increased by $421 (95% CI, 149 to 692) in the same period.

Conclusions The ACA was associated with reduced OOP for health services but increased premium contributions, resulting in no significant impact on perceived financial burden among non-elderly cancer survivors.

Implications for cancer survivors The financial hardship of cancer survivorship points to the need for the development of provisions that help cancer patients reduce both perceived and materialized burden of cancer care under ongoing health reform.

Keywords Financial burden of cancer care · Affordable Care Act · Out-of-pocket spending · Insurance premiums

Introduction

Cancer is the second leading cause of death and the costliest medical condition in the USA [1–3]. There were 15.5 million people with a history of cancer in 2016, and this number is expected to rise to over 18.1 million in 2020 [1,2]. Along with this increase in cancer prevalence, costs of cancer care are also projected to increase to approximately $173 billion in 2020, almost 40% increase from 2010 [2]. It is well documented that cancer survivors have higher out-of-pocket (OOP) expenditures [4,5] and face greater financial burden on their medical care [6–9]. Indeed, cancer survivorship has an adverse effect on the financial well-being of the patient as well as their families, depleting income and financial assets [8] and even increasing the risk of medical bankruptcy [10]. A greater share of medical expenses by survivors also often creates barriers to access to care [11] and limit their choices of treatment [12], resulting in poor health outcomes. As a result, dealing with this "financial toxicity" among cancer survivors has become a great concern in US health care [8].

It has been 8 years since the Affordable Care Act (ACA) was signed into law with the aim of expanding insurance coverage and improving access to care [13]. As one can infer from its name, one of the main goals of the ACA was to lessen the financial burden of health care, mostly by expanding health insurance coverage [13,14]. Extensive evidence has been documented that the provisions of ACA were successful in achieving

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its proposed goals, the national uninsured rate and OOP spending for health care decreased significantly [15–17]. However, current evidence concerning the impact of ACA is somewhat limited to the general population; little is known about its impact on the financial burden among cancer survivors. Considering the critical economic and clinical consequences of financial toxicity of cancer [8,10], it is essential to assess the impact of the ACA's provisions on financial burden associated with cancer care. No known studies to date have examined cancer survivors' perceived financial hardship and OOP expenditures after the ACA implementation.

Given the coverage expansion among cancer survivors [18], whether the ACA reduced burden of cancer care remains an important question. After the ACA implementation, the uninsured rate among cancer survivors decreased to 7.7% (a 38% decrease from 2012) [18]. Moreover, recent studies demonstrated that the provisions of ACA-reduced OOP spending for those with the low income [16,17] and chronic conditions [19]. Whether similar changes have occurred among cancer survivors is still unknown. Therefore, to fill this gap in the literature, we aimed to assess changes in self-reported financial burden associated with cancer care and total OOP expenditures between pre- and post-ACA periods. We also evaluated differences in those changes by insurance types among cancer survivors in the USA.

Methods

Data and analytic sample

We used data from the Medical Expenditure Panel Survey (MEPS) Household Component and Experiences with Cancer Survivorship Survey Supplement (ECSS) 2011 and 2016. MEPS-ECSS is nationally representative survey of cancer survivors, developed in collaboration with the National Cancer Institute, American Cancer Society, the Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality to improve the quality of data in MEPS for estimating the cancer survivorship burden in the USA. For sampled US households with at least one cancer survivor, the MEPS-ECSS collects information on both (subjective) perceptions of household financial burden associated with the diagnosed/treated cancer and (objective) measures of out-of-pocket spending on medical care and on health insurance premiums [20,21]. The survey was administered in 2011 and 2016 with an average response rate of 85.6%. We used the two waves of the MEPS-ECSS to examine aspects of financial burden in a pre-ACA year (2011) and a post-ACA year (2016).

A total of 4407 US adults aged 18 or older with a confirmed diagnosis of any cancer and cancer treatment were eligible and completed the MEPS-ECSS in 2011 and 2016 (two distinct samples of family with cancer survivors). Given that the ACA coverage expansion targeted non-elderly population (those aged ≥ 65 are covered by Medicare) [13,14,22], we restricted our sample to individuals with cancer diagnosis between ages 18 and 64 years ($n = 2036$). Of those, we excluded those who only reported non-melanoma skin cancer ($n = 5$) because they are not classified as cancer survivors [23]. We also excluded those with non-positive survey weights ($n = 876$) because they are considered as missing in the survey-design adjusted analyses. These exclusion criteria resulted in our final analytic sample of 1155 cancer survivors aged 18–64 ($n = 665$ in 2011 and $n = 490$ in 2016).

Primary outcomes: self-reported financial hardship and high-burden spending

Our primary outcome of interest was whether there was a difference in financial burden associated with cancer care between 2011 (pre-ACA) and 2016 (post-ACA). We considered and used two aspects of financial burden: subjective (self-reported financial hardship) and objective (total out-of-pocket expenditure) measures. Subjective financial burden (self-reported, hereafter) was assessed using four questions related to the effect of cancer care on finance, following the previous approaches [6]. Respondents were asked if they ever (1) were unable to cover costs of medical care, (2) had to file for bankruptcy, (3) borrowed money or went into debt, or (4) worried about paying large medical bills because of cancer care. We defined cancer survivors with self-reported financial burden if they responded "Yes" to any of those four questions. The objective financial burden was assessed using the amount of total OOP expenditures (OOP for health services use plus premium payments) relative to annual family income. OOP spending on health services use was a summation of self-payment, deductibles, copayments, and other cost-sharing for ambulatory care, inpatient stay, prescription drugs or other types of care services [24]. Premium payments were self-reported amounts paid out-of-pocket for insurance coverage (for 2016 data, the amounts were adjusted to reflect the reduction achieved from premium subsidies under the ACA) [24]. Given shared financial resources and health insurance coverage within a family [25], we constructed family-level measure and defined cancer survivors with financial burden (high-burden spending, hereafter), if they incurred total OOP expenditure in excess of 10% or 20% of family income, respectively. These thresholds have been generally used for the indicator of high-burden spending on healthcare [17,25].

Cancer survivor characteristics

Cancer survivors' sociodemographic variables included age groups (18–44, 45–54, 55–59, and 60–64 years), sex, race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), educational attainment (less than high school, high school degree or general equivalency diploma,

some college, and college graduate or higher), marital status (married and unmarried), employment (employed and unemployed), family income level (federal poverty level [FPL] < 200% as low income, FPL 200–400% as middle income, and FPL > 400% high income), census region (Northeast, Midwest, South, West), health insurance coverage (private, public, and uninsured). Private insurance types were further defined for two groups (employment-based coverage [group] and individually purchased coverage [non-group]). Clinical characteristics included number of comorbidities (0, 1, and 2 or more), time since last cancer treatment (on treatment [current or < 1 year], 1–4 years, 5–9 years, ≥ 10 years, and never treated/unknown), and health scores (SF-12 Health Survey) [24]. Comorbidity conditions were assessed based on the MEPS priority condition that includes hypertension, high cholesterol, coronary heart diseases, angina, myocardial infarction, other heart diseases, stroke, emphysema, and diabetes [26]. Time since last cancer treatment was defined using two questions asking the person's cancer diagnosis and treatment history, given the high correlation between treatment status and time since diagnosis [9].

Statistical analysis

Cancer survivors' characteristics compared using the survey-design adjusted Wald *F* tests. We estimated annual OOP expenditures for each type of health services (ambulatory care, inpatient stay, prescription drugs, and other types of services) and premium payments using generalized linear regressions (GLM) with a gamma distribution and log link to account for skewness in the distribution of health expenditures. We imposed $1 floor of OOP to handle with zero expenditures (7.6% of the sample) in the GLM model [27]. All expenditures were inflated to 2016 dollar value using the consumer price index [28]. For the main analysis, linear regressions were modeled to estimate changes in the prevalence of the self-reported financial hardship and high-burden spending between pre-and post-ACA periods. All multivariable models were adjusted for differences in key characteristics that may affect health services utilization and expenditures, including age, sex, race/ethnicity, marital status, employment, census region, number of comorbidities, and time since cancer treatment, and the SF-12 health scores [9,27,29].

To further investigate the impact of ACA coverage expansion, the changes in the financial burden outcomes were compared for the four types of health insurance (group-based private, non-group private, any public, and uninsured) in subgroup analyses. Sensitivity analyses were also conducted to explore the changes in the main outcomes by age, race/ethnicity, family income level, and time since last treatment. Our analytic data were analyzed using SAS 9.4 (SAS Institute) and accounted for the complex survey design to produce nationally representative estimates. This study used publicly available deidentified data and was deemed exempt by the University of Florida Institutional Review Board.

Results

Characteristics of non-elderly cancer survivors between 2011 ($n = 655$) and 2016 ($n = 490$) were comparatively similar (Table 1). Cancer survivors who reported self-reported financial burden tended to be younger, racial/ethnic minority, with low family income, or uninsured. Concerning high-burden spending, those with total OOP expenditure exceeding 20% of family income were likely to be female, married, with low family income, or insurance publicly funded. The full information on relationships of cancer survivor characteristics with the financial burden outcomes is available in Appendix Table 4.

Changes in self-reported financial hardship

There was no apparent difference in unadjusted distribution of self-reported financial hardship between 2011 and 2016 (Fig. 1a; $P = 0.831$); specifically, no significant changes were observed for all financial hardship indicators: unable to cover the cost associated with cancer care (adjusted difference [AD] − 1.0%, 95% CI, − 4.7 to 2.9, $P = 0.656$), had to borrow money or go into debt (AD − 1.0%, 95% CI, − 4.4 to 2.3, $P = 0.542$), filed for bankruptcy (AD 0.0, 95% CI, − 1.3 to 1.4, $P = 0.904$); and worried about paying large medical bills (AD 1.6, 95% CI, − 3.9 to 7.2, $P = 0.562$; Table 2).

Changes in high-burden spending and OOP expenditures

The unadjusted proportions of cancer survivors having high-burden spending did not change significantly after the ACA (Fig. 1b; $P = 0.644$). However, the mean OOP decreased significantly by $268 (95% CI, − $384 to − $152) from $1513 in 2011 to $1245 in 2016 (Fig. 1c and Table 2). The reduction in OOP for inpatient stay and prescription drugs contributed most to this change (Fig. 1c). The mean premium payments increased by $420 (95% CI, $149 to $692) from $4500 in 2011 to $4920 in 2016. The adjusted prevalence of cancer survivors with total OOP exceeding 10% (AD − 1.6, 95% CI, − 7.4 to 4.2) or 20% (AD − 2.2, 95% CI, − 5.8 to 1.4) of their income also did not change significantly ($P = 0.587$ and 0.220, respectively; Table 2).

Subgroup analyses by health insurance type

The prevalence of self-reported financial hardship or having high-burden spending did not change for those with private insurance types (Table 3). For those with

Table 1 Baseline information of cancer survivors aged 18–64: MEPS-experiences with cancer survivorship supplement 2011 and 2016

	Characteristics of cancer survivors				
	Year 2011		Year 2016		
	Sample $N = 665$		Sample $N = 490$		
	Population estimate = 9,366,097		Population estimate = 7,929,889		
	No.	Weighted %, (95% CI)	No.	Weighted %, (95% CI)	*P* value
Age group					0.617
18–44	121	16.8 (13.7–20.0)	103	18.9 (15.1–22.7)	
45–54	207	31.0 (26.4–35.6)	137	27.6 (22.9–32.3)	
55–59	137	20.8 (17.1–24.5)	115	23.3 (18.2–28.3)	
60–64	200	31.4 (26.5–36.2)	135	30.2 (24.6–35.8)	
Sex					0.672
Female	455	63.4 (59–67.9)	323	62.0 (56.4–67.5)	
Male	210	36.6 (32.1–41.0)	167	38.0 (32.5–43.6)	
Race/ethnicity					0.347
Non-Hispanic White	491	85.0 (82.1–87.9)	322	82.7 (79.4–85.9)	
Non-Hispanic Black	77	6.1 (4.6–7.6)	53	5.4 (3.6–7.1)	
Hispanic	74	6.5 (4.4–8.6)	95	8.2 (6.2–10.2)	
Other	23	2.4 (1.2–3.6)	20	3.8 (1.7–5.8)	
Education					0.653
Less than high school	70	6.9 (4.8–8.9)	59	6.6 (4.6–8.6)	
High school or GED	197	23.7 (19.7–27.7)	148	27.9 (22.7–33.0)	
Some College	171	27.6 (23.6–31.6)	133	25.8 (21.1–30.5)	
College or higher	227	41.8 (36.7–46.9)	150	39.7 (34.3–45.1)	
Marital status					0.620
Married	386	64.6 (60.1–69.2)	297	66.3 (61.3–71.3)	
Unmarried	279	35.4 (30.8–39.9)	193	33.7 (28.7–38.7)	
Family income level					0.012
Low income (FPL < 200%)	215	21.8 (18.2–25.4)	189	26.9 (22.2–31.5)	
Middle income (FPL 200–400%)	187	26.8 (22.3–31.4)	105	18.6 (14.7–22.5)	
High Income (FPL > 400%)	263	51.4 (46.0–56.8)	196	54.5 (49.0–60.0)	
Total family income	$68,757		$77,555		0.217
Median (IQR), 2016$	($35,342–$112,391)		($30,708–$119,102)		
Employment					0.434
Employed	416	65.4 (60.6–70.1)	300	68.2 (63.4–72.9)	
Not Employed	249	34.6 (29.9–39.4)	190	31.8 (27.1–36.6)	
Census region					0.258
Northeast	111	17.5 (14.2–20.9)	88	17.9 (14.2–21.6)	
Midwest	158	22.4 (17.7–27.1)	103	20.1 (15.8–24.4)	
South	260	41.6 (35.9–47.4)	180	38.2 (33.0–43.3)	
West	136	18.4 (15.3–21.4)	119	23.8 (19.4–28.1)	
Health insurance type					0.001
Private, employer/group	334	57.8 (53.2–62.5)	222	54.4 (48.8–60.1)	
Private, individual/non-group	137	21.2 (17.3–25.0)	105	22.9 (18.3–27.5)	
Any public	124	13.0 (10.1–15.8)	138	19.4 (15.5–23.2)	
Uninsured	70	8.0 (5.7–10.3)	25	3.3 (1.8–4.8)	
# of comorbidities					0.243
0	223	33.5 (29.4–37.6)	145	29.3 (25.0–33.6)	
1	168	28.2 (24.3–32.2)	148	32.3 (27.7–36.8)	
2+	274	38.3 (34.3–42.2)	197	38.4 (33.7–43.1)	
Time since last cancer treatment					0.249
On treatment: current or less than 1 year	147	24.3 (20.0–28.7)	124	25.4 (20.8–30.0)	
1 to < 5 years ago	165	25.1 (21.0–29.2)	114	23.1 (18.4–27.9)	
5 to < 10 years ago	123	16.2 (13.1–19.2)	88	19.8 (15.5–24.1)	
10+ years ago	149	22.8 (19.6–26.0)	88	17.9 (13.7–22.1)	
Never treated/unknown	81	11.6 (9.0–14.2)	76	13.7 (10.0–17.5)	

Table 1 (continued)

	Characteristics of cancer survivors				
	Year 2011		Year 2016		
	Sample $N = 665$		Sample $N = 490$		
	Population estimate = 9,366,097		Population estimate = 7,929,889		
	No.	Weighted %, (95% CI)	No.	Weighted %, (95% CI)	*P* value
Health score (SF-12), mean (SE)					
Physical component	46.9 (0.5)		46.7 (0.6)		0.813
Mental component	48.9 (0.4)		50.3 (0.5)		0.046
Health care costs, median (IQR), 2016$					
Total health expenditure	$4512 ($1291–$14,149)		$3685 ($1279–$9826)		0.292
Total out-of-pocket	$809 ($274–$1866)		$477 ($128–$1244)		< 0.001
Premium spending	$3284 ($1890–$5558)		$3629 ($1693–$6164)		0.444

GED general equivalency diploma, *FPL* federal poverty level, *SF-12* 12-item short form survey, *SE* standard error, *IQR* interquartile range

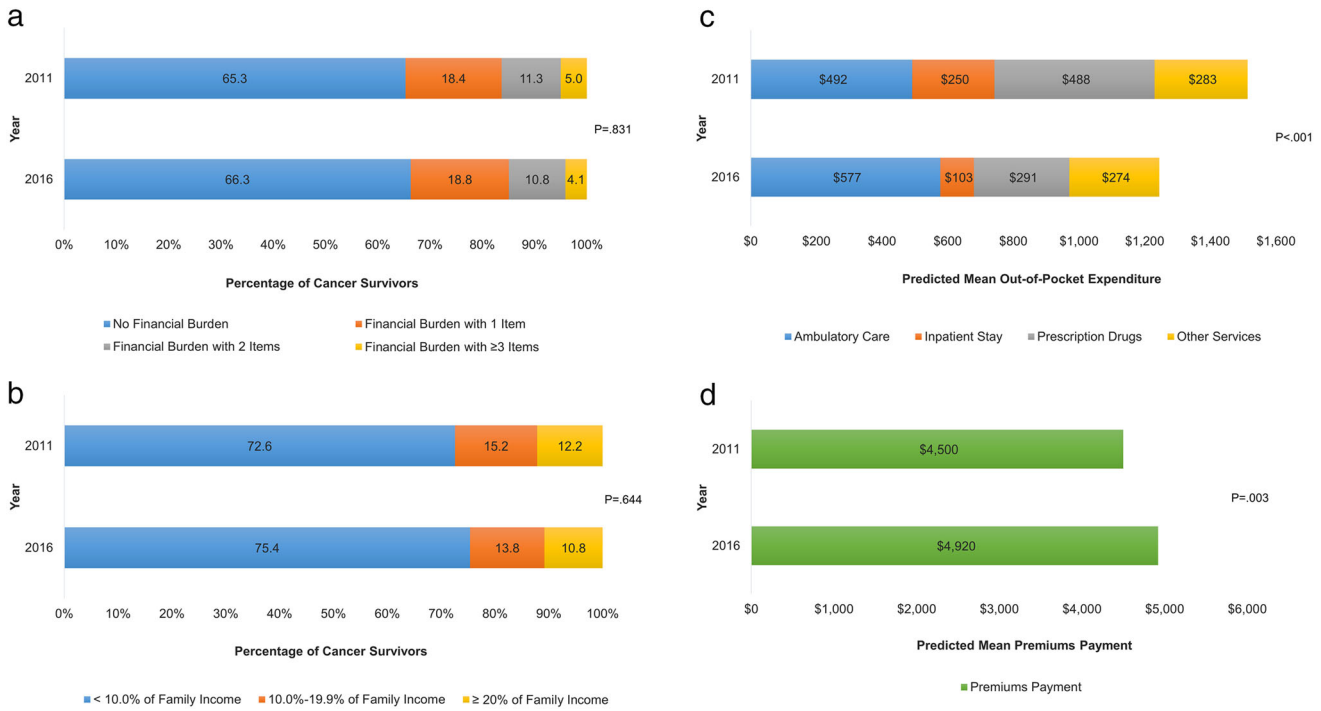

Fig. 1 Distribution of self-reported financial hardship (**a**), high-burden spending (**b**), mean out-of-pocket spending by service types (**c**), and mean premiums payment (**d**) among cancer survivors between 2011 and 2016. Items of self-reported financial hardship include (1) unable to cover costs of medical care, (2) had to file for bankruptcy, (3) borrowed money or went into debt, and (4) worried about paying large medical bills because of cancer care. Estimates are weighted to be nationally representative using recommended stratification, clustering, and weighting by Agency for Healthcare Research and Quality. Predicted values for expenditure were obtained from multivariable generalized linear model (gamma distribution and log link) adjusting for age, sex, race/ethnicity, education, marital status, employment, family income level, insurance type, number of comorbidities, time since last cancer treatment, census region, and SF-12 physical and mental component summary scores

Table 2 Changes in self-reported financial burden and high-burden spending among cancer survivors between 2011 and 2016

	Year 2011 Weighted %, (95% CI)	Year 2016 Weighted %, (95% CI)	Absolute difference 2016 vs. 2011, % change (95% CI)	Adjusted difference 2016 vs. 2011, % change (95% CI)	*P* value
Self-reported financial burden					
Unable to cover cost of medical care	15.6 (12.6 to 18.5)	14.5 (11.1 to 17.9)	− 1.1 (− 5.4 to 3.3)	− 1.0 (− 4.7 to 2.9)	0.656
Had to borrow money or go into debt	11.0 (8.4 to 13.8)	9.0 (6.2 to 11.2)	− 2.4 (−5.9 to 1.2)	− 1.0 (− 4.4 to 2.3)	0.542
Filed for bankruptcy	1.8 (0.7 to 2.9)	1.4 (0.5 to 2.4)	− 0.3 (− 1.7 to 1.0)	0.0 (− 1.3 to 1.4)	0.904
Worried about paying large medical bills	28.5 (24.8 to 32.2)	28.3 (23.6 to 33.1)	−0.1 (− 6.0 to 5.6)	1.6 (− 3.9 to 7.2)	0.562
Any financial burden	34.7 (30.8 to 38.7)	33.7 (28.4 to 39.0)	− 1.0 (− 7.5 to 5.5)	− 0.4 (− 6.4 to 5.6)	0.892
High-burden spending [a]					
Out-of-pocket spending for health services, 2016$	1513 (1414 to 1610)	1245 (1175 to 1314)	− 268 (− 384 to −152)	− 222 (− 301 to −144)	<0.001
Premium payments, 2016$	4500 (4316 to 4686)	4920 (4724 to 5117)	420 (149 to 692)	245 (40 to 450)	0.019
Total out-of-pocket > 10% of family income	27.1 (23.0 to 31.2)	24.6 (21.0 to 29.1)	− 2.5 (− 8.6 to 3.7)	− 1.6 (− 7.4 to 4.2)	0.587
Total out-of-pocket > 20% of family income	12.2 (9.6 to 14.8)	10.8 (7.9 to 13.8)	− 1.3 (− 5.2 to 2.6)	− 2.2 (− 5.8 to 1.4)	0.220

public insurance, the prevalence of having high-burden spending declined significantly (AD − 12.7%, 95% CI, − 22.4 to − 3.0). The amount of OOP for medical care decreased significantly for all insurance types in 2016, from − $128 for respondents with any public insurance to − $429 for uninsured respondents ($P < 0.01$ for all). However, concerning total OOP spending (OOP for medical care plus any premium contributions), there was significant reduction observed only for those with public insurance (AD − $886, 95% CI, − $1470 to − $302, $P < 0.001$). Among those with private insurance, the premium spending after the ACA was significantly increased for those with employer/group-based insurance type (AD $301, 95% CI, $57 to $467, $P = 0.012$), concerning total OOP spending (OOP for medical care plus any premium contributions),

Sensitivity analyses

Consistent with main findings, no significant changes in self-reported financial hardship were observed across these subgroups ($P > 0.05$ for all; Fig. 2a). However, we found that the prevalence of high-burden spending after the ACA was significantly decreased for those middle-aged, Hispanic, those with low-income, or who received last cancer treatment more than 10 years ago (Fig. 2b).

Discussion

This analysis of a national survey of cancer survivors demonstrated mixed effects of the implementation of ACA on the cancer survivor self-reported financial hardship. While there was no significant changes had been observed in the prevalence of self-reported subjective hardship, the study found statistically significant reduction on some self-reported objective hardship. In 2011 and 2016, one-third of non-elderly cancer survivors (2.7 million) reported having at least one indicator of financial hardship associated with cancer care, and nearly 11% of them (0.9 million), spent more than 20% of their family income on their medical care. For objective hardship, there was a statistically significant decline in OOP spending for health services between the study periods. However, the absolute amount of reduction may have been offset by the increased premium payments across insurance type. Subgroup analyses reveal that the most significant decline in objective financial burden occurred among those with public insurance. However, no significant decrease in self-reported subjective financial burden coincided, and they had the highest prevalence of reporting any of financial hardship. Taken together, our findings suggest that the ACA coverage expansion may not be associated with a reduction in the financial burden of health care among cancer survivors in the USA.

Several studies have reported that the ACA's provisions reduced OOP spending for health care overall; [16,17,19]

Table 3 Changes in financial burden and total out-of-pocket contributions among cancer survivors between 2011 and 2016, by health insurance type

	Year 2011 Estimate, (95% CI)	Year 2016 Estimate, (95% CI)	Absolute difference 2016 vs. 2011, difference (95% CI)	Adjusted difference 2016 vs. 2011, difference (95% CI)	*P* value
Any self-reported financial burden, %					
Private, employer/group	30.4 (25.0 to 36.0)	29.5 (22.0 to 36.9)	− 1.0 (− 10.3 to 8.3)	1.1 (− 7.5 to 9.6)	0.804
Private, individual/non-group	30.4 (21.1 to 39.6)	34.4 (23.6 to 45.2)	4.1 (− 10.1 to 18.3)	0.0 (− 15.3 to 15.2)	0.995
Any public	47.2 (36.6 to 57.9)	44.1 (34.0 to 54.2)	− 3.1 (− 17.8 to 11.5)	− 4.0 (− 18.5 to 10.5)	0.588
Uninsured	56.9 (43.1 to 70.6)	36.9 (14.9 to 58.9)	− 19.9 (− 45.9 to 5.9)	− 1.9 (− 34.2 to 30.5)	0.909
High-burden spending, % (OOP > 20% of family income)					
Private, employer/group	8.0 (5.8 to 10.2)	10.4 (7.4 to 13.5)	2.4 (− 8.4 to 3.5)	1.8 (− 5.9 to 2.2)	0.368
Private, individual/non-group	14.8 (8.5 to 21.1)	11.3 (4.5 to 18.6)	− 3.5 (−13.1 to 6.1)	− 1.0 (− 10.5 to 8.5)	0.837
Any public	24.1 (15.4 to 32.7)	11.5 (5.5 to 17.5)	− 12.6 (− 23.1 to − 2.1)	− 12.7 (− 22.4 to − 3.0)	0.010
Uninsured	16.3 (7.3 to 25.4)	10.4 (3.0 to 23.9)	− 6.0 (− 22.2 to 10.2)	− 6.6 (− 27.7 to 14.4)	0.534
Amount of OOP for medical care, 2016$					
Private, employer/group	1279 (1074 to 1484)	1041 (836 to 1246)	− 238 (−528 to 52)	− 241 (− 335 to − 147)	< 0.001
Private, individual/non-group	1463 (1049 to 1877)	1180 (827 to 1532)	− 283 (− 827 to 260)	− 271 (− 461 to − 81)	0.005
Any public	668 (481 to 856)	535 (357 to 712)	− 134 (− 392 to 124)	− 128 (− 203 to − 53)	0.001
Uninsured	1221 (686 to 1756)	972 (351 to 1593)	− 249 (− 1069 to 571)	− 429 (−633 to −225)	< 0.001
Annual premium payments, 2016$ [a]					
Private, employer/group	3723 (3285 to 4160)	4413 (3820 to 5006)	691 (− 47 to 1428)	301 (57 to 467)	0.012
Private, individual/non-group	3299 (2269 to 4329)	3584 (2377 to 4790)	285 (− 1302 to 1871)	52 (− 542 to 646)	0.863
Any public	1236 (485 to 1987)	226 (72 to 380)	− 1010 (− 1776 to − 244)	− 310 (− 902 to 282)	0.303
Uninsured	524 (127 to 921)	820 (226 to 1466)	296 (− 823 to 1415)	357 (− 241 to 955)	0.239
Total OOP (medical care + premium), 2016$					
Private, employer/group	5097 (4034 to 6160)	5453 (4697 to 6210)	357 (− 548 to 1262)	225 (− 397 to 846)	0.484
Private, individual/non-group	4767 (3869 to 5665)	4962 (4020 to 5904)	195 (− 1106 to 1495)	218 (− 1044 to 1480)	0.735
Any public	1963 (1522 to 2405)	890 (492 to 1287)	− 1073 (− 1667 to − 479)	− 886 (− 1470 to − 302)	< 0.001
Uninsured	1930 (1512 to 2348)	1508 (803 to 2356)	− 350 (− 1231 to 531)	− 202 (− 981 to 577)	0.609

[a] Premium contributions for those with public and the uninsured were incurred if they held private coverage for part of the year or were covered by private coverage of other family members

however, our study suggests the overall subjective financial burden is still not relieved. As reported in our study, 33.7% of cancer survivors still worried about paying their medical bill for cancer care, borrowed money to cover the cost, or filed bankruptcy in 2016, only 1% reduction from 34.7% in 2011. Cancer treatment is very expensive that may raise the cancer

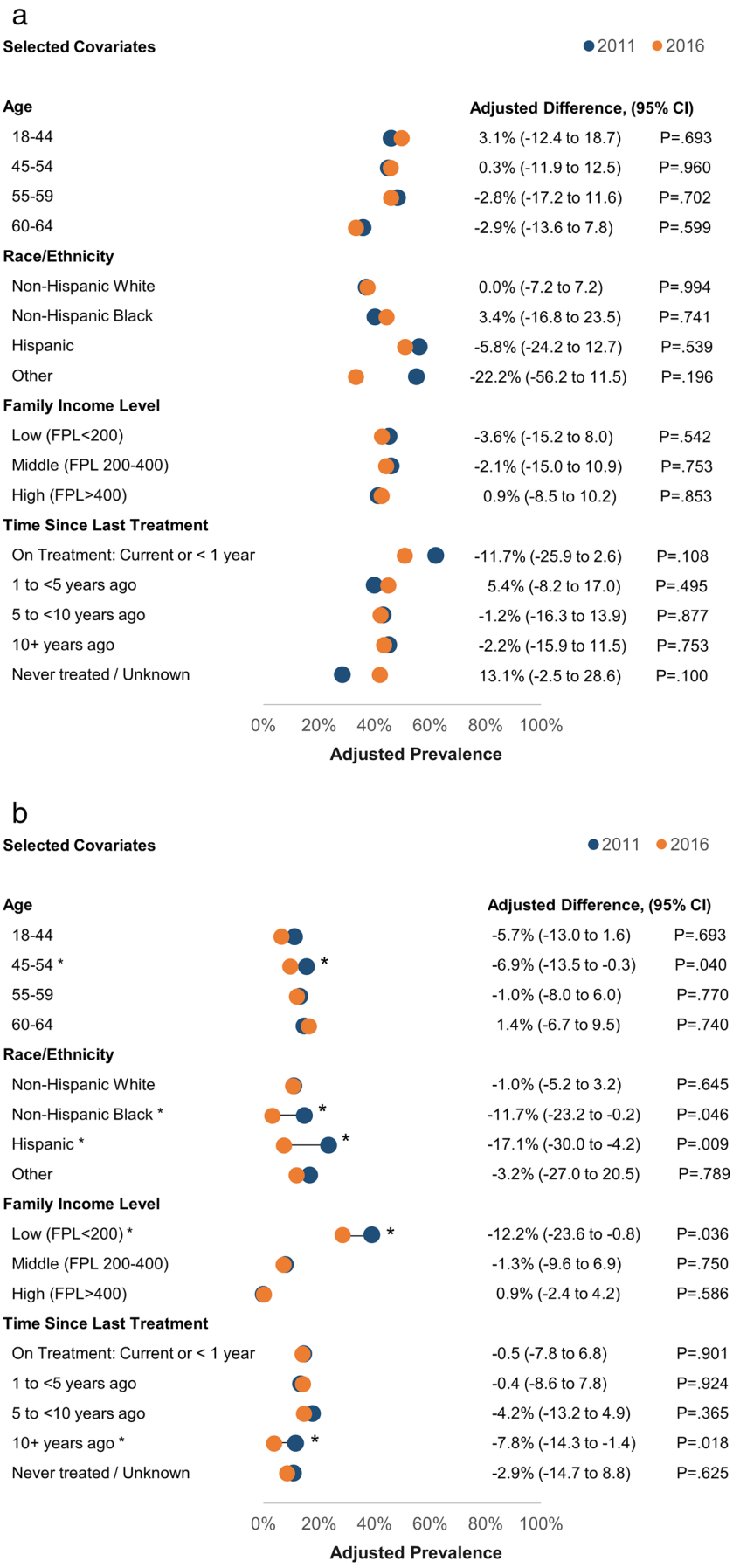

Fig. 2 Prevalence of reporting any financial hardship (**a**) and high-burden spending (**b**) among cancer survivors between 2011 and 2016, by selected covariates. Estimates are weighted to be nationally representative using recommended stratification, clustering, and weighting by Agency for Healthcare Research and Quality. *Difference between 2011 and 2016 is statistically significant at $P < 0.05$

patients' spending to the OOP maximum rapidly [8]. The average annual medical expenditure among those with cancer was more than twice than that of those with no history of cancer [23,30]. Families with cancer survivors may also have to reduce their monthly household expenses on necessities [31]. Consequently, the decreased OOP under the ACA may not be significant enough to be perceived among non-elderly cancer survivors as a whole. The adjusted reduction of total amount of OOP in our study ranged from $128 to $271 across the insurance type, considered a trivial amount compared with the actual average OOP spending of $1245 in 2016.

It is also plausible that the overall increase in premiums may outweigh the amount of OOP saved by less spending on health services among cancer survivors. We found that more than 77% of non-elderly cancer survivors had private insurance types, group-based or non-group/individually purchased, and incurred greater premium spending after the ACA ($447 more as combined; data not shown). Premiums continued to rise for those with group-based (e.g., employment); in 2016, the average employee contributions for family coverage were $5277, which was a 28% increase from $4129 in 2011 (compared with 11% increase in average workers' earnings in the same period) [32]. For those with individually purchased plans, premiums may not be in a range where they could afford; even with ACA subsidies, those in coverage gap [33] or who newly gained marketplace plans depending on their income level may feel their contributions to premiums not affordable [34].

The decrease in mean OOP expenditures in this study appears to be driven by reduced spending for inpatient care and prescription drugs. Given that ACA was designed to promote primary care by providing various incentives through patient-centered care and value-based payment models [35,36], our findings may reflect a national shift of care delivery from inpatient to ambulatory care setting in the past several years [35]. It also seems plausible that, under these national efforts [35,36], patient-centered care has been encouraged in cancer care [37], promoting the patient-clinician discussion of financial toxicity of cancer care and meaningful use of high-value cancer drugs [8]. A large prescription data-based study also found that, although those who gained coverage under the ACA had an increase in the number of prescription fills, OOP spending on prescription drugs did not increase [19]. Consistent with previous studies on general population [17,38], our sensitivity analyses also suggest that racial/ethnic minorities or those with the low-income experienced a significant reduction in total OOP spending as intended under the ACA.

Several limitations should be noted in this study. First, the pre-and-post study design does not allow us to determine the causation between the ACA provisions and the change in financial hardship. However, our findings based on population-based data representing pre-and post-ACA periods likely reflect the impact of ACA implementation. Second, the recent economic recovery and growth may have influenced the study outcomes [39]. To address this, our study controlled for family income and employment status, two proxy of potential economic confounders. Although there were some differences in family income distribution between 2011 and 2016, it was likely to be national trends [39], and these differences in the income distribution were consistent when compared with the general population. Third, the data we used was from the year 2016, only 2 years after the ACA implementation; the study period may be too short to observe the full impact of ACA on financial hardship. Lastly, the self-reported financial hardship and health expenditures in the survey data are always subject to recall bias. Despite these limitations, the MEPS-ECSS is a widely used data source that can be representative of the population as having been diagnosed with or treated for cancer [20,21]. Use of two waves of the MEPS-ECSS provided us a unique opportunity to assess nationally representative change in financial hardship among cancer survivors in the USA.

Conclusions

Following the implementation of ACA, the financial burden associated with cancer care in non-elderly cancer survivor seems to be mixed in the USA. Although out-of-pocket spending for medical services decreased among cancer survivors with greater reduction in those with lower family income or racial/ethnic minority, the reduction on the self-reported financial hardship were yet to be observed among the cancer survivors. Future study with more matured data is needed to examine the effect of ACA on self-reported financial hardship. Our findings also suggest the need for the development of provisions that help cancer patients reduce both perceived and materialized burden of cancer care.

Authors' contribution • Study conception and design: Hong and Huo
• Acquisition, analysis, or interpretation of data: All authors
• Drafting of manuscript: Hong
• Critical revision of the manuscript for important intellectual content: Smith, Mainous, and Huo
• Statistical analysis: Hong and Huo
• Administrative, technical, or material support: Hong and Xie
• Study supervision: Huo and Mainous

Compliance with ethical standards

Conflict of interest The authors declare that they had no conflict of interest.

Ethical approval This study was deemed exempt from review by the University of Florida Institutional Review Board because the use of publicly available dataset did not constitute human subjects research.

Informed consent Since we used deidentified data, informed consent from the participants was not required.

Appendix

Table 4 Relationships between cancer survivor characteristics and financial burden outcomes

	Any self-reported financial hardship					High-burden spending (total out-of-pocket > 20% of family income)				
	Yes		No			Yes		No		
	Sample $N = 477$		Sample $N = 708$			Sample $N = 163$		Sample $N = 992$		
	Population estimate = 5,922,368		Population estimate = 11,373,618			Population estimate = 2,001,021		Population estimate = 15,294,966		
	No.	Weighted %, (95% CI) [a]	No.	Weighted %, (95% CI) [a]	*P* value [b]	No.	Weighted %, (95% CI) [a]	No.	Weighted %, (95% CI) [a]	*P* value [b]
Year					0.741					0.489
2011	255	34.7 (30.9–38.5)	410	65.3 (61.5–69.1)		103	12.2 (9.6–14.8)	562	87.8 (85.2–90.4)	
2016	191	33.7 (28.8–38.6)	298	66.3 (61.4–71.2)		60	10.8 (7.9–13.8)	430	89.2 (86.2–92.1)	
Age group					0.001					0.544
18–44	96	39.3 (32.2–46.4)	128	60.7 (53.6–67.8)		32	9.4 (5.9–12.8)	192	90.6 (87.2–94.1)	
45–54	141	36.9 (31.0–42.8)	203	63.1 (57.2–69.0)		50	12.6 (9.2–16.0)	294	87.4 (84.0–90.8)	
55–59	106	39.8 (32.4–47.3)	146	60.2 (52.7–67.6)		34	10.8 (6.3–15.3)	218	89.2 (84.7–93.7)	
60–64	104	24.8 (20.3–29.3)	231	75.2 (70.7–79.7)		47	12.4 (8.1–16.7)	288	87.6 (83.3–91.9)	
Sex					0.064					0.009
Female	313	36.9 (32.8–40.9)	465	63.1 (59.1–67.2)		113	13.4 (10.7–16.1)	665	86.6 (83.9–89.3)	
Male	134	29.8 (24.3–35.4)	243	70.2 (64.6–75.7)		50	8.5 (6.0–11.0)	327	91.5 (89.0–94.0)	
Race/ethnicity					< 0.001					0.166
Non-Hispanic White	280	31.5 (27.9–35.2)	533	68.5 (64.8–72.1)		102	10.6 (8.4–12.8)	711	89.4 (87.2–91.6)	
Non-Hispanic Black	55	44.5 (34.6–54.5)	75	55.5 (45.5–65.4)		20	13.1 (7.3–18.8)	110	86.9 (81.2–92.7)	
Hispanic	94	55.7 (47.2–64.2)	75	44.3 (35.8–52.8)		32	18.4 (10.6–26.2)	137	81.6 (73.8–89.4)	
Other	18	37.9 (20.8–55.1)	25	62.1 (44.9–79.2)		9	19.1 (6.7–31.4)	34	80.9 (68.6–93.3)	
Education					< 0.001					0.005
Less than high school	68	54.2 (44.0–64.5)	61	45.8 (35.5–56.0)		21	15.2 (8.4–22.0)	108	84.8 (78.0–91.6)	
High school or GED	132	36.9 (30.4–43.4)	213	63.1 (56.6–69.6)		61	17.3 (12.3–22.3)	284	82.7 (77.7–87.7)	
Some college	140	42.9 (35.7–50.1)	164	57.1 (49.9–64.3)		41	11.2 (7.9–14.4)	263	88.8 (85.6–92.1)	
College or higher	107	23.6 (19.7–27.5)	270	76.4 (72.5–80.3)		40	7.6 (4.6–10.7)	337	92.4 (89.3–95.4)	

Table 4 (continued)

	Any self-reported financial hardship					High-burden spending (total out-of-pocket > 20% of family income)				
	Yes		No			Yes		No		
	Sample $N = 477$		Sample $N = 708$			Sample $N = 163$		Sample $N = 992$		
	Population estimate = 5,922,368		Population estimate = 11,373,618			Population estimate = 2,001,021		Population estimate = 15,294,966		
	No.	Weighted %, (95% CI) [a]	No.	Weighted %, (95% CI) [a]	*P* value [b]	No.	Weighted %, (95% CI) [a]	No.	Weighted %, (95% CI) [a]	*P* value [b]
Marital status					0.062					0.016
Married	197	38.4 (33.5–43.2)	275	61.6 (56.8–66.5)		87	14.9 (11.8–18.0)	385	85.1 (82.0–88.2)	
Unmarried	250	32.1 (27.9–36.2)	433	67.9 (63.8–72.1)		76	9.8 (7.2–12.4)	607	90.2 (87.6–92.8)	
Family income level					< 0.001					< 0.001
Low income (FPL < 200%)	187	42.9 (37.7–48.0)	217	57.1 (52.0–62.3)		125	33.1 (27.3–38.9)	279	66.9 (61.1–72.7)	
Middle income (FPL 200%–400%)	121	39.8 (33.6–45.9)	171	60.2 (54.1–66.4)		32	12.3 (7.6–17.0)	260	87.7 (83.0–92.4)	
High income (FPL > 400%)	139	27.9 (23.3–32.5)	320	72.1 (67.5–76.7)		6	1.4 (0.1–2.8)	453	98.6 (97.2–99.9)	
Total family income, median (IQR), 2016$	55,931 (26174–92,913)		81,070 (37189–119,988)		< 0.001	19,501 (8675–36,490)		79,173 (39996–119,566)		< 0.001
Employment					0.273					0.016
Employed	181	36.5 (31.7–41.3)	258	63.5 (58.7–68.3)		99	19.9 (15.0–24.7)	340	80.1 (75.3–85.0)	
Not employed	266	33.1 (29.2–37.0)	450	66.9 (63.0–70.8)		64	7.4 (5.4–9.4)	652	92.6 (90.6–94.6)	
Census region					0.031					0.075
Northeast	63	26.2 (20.5–31.8)	136	73.8 (68.2–79.5)		25	7.9 (4.9–10.8)	174	92.1 (89.2–95.1)	
Midwest	104	37.7 (30.5–44.9)	157	62.3 (55.1–69.5)		42	14.6 (10.2–18.9)	219	85.4 (81.1–89.8)	
South	192	36.8 (32–41.6)	248	63.2 (58.4–68)		65	12.0 (8.6–15.3)	375	88.0 (84.7–91.4)	
West	88	32.6 (25.5–39.7)	167	67.4 (60.3–74.5)		31	10.8 (6.0–15.6)	224	89.2 (84.4–94.0)	
Health insurance type					< 0.001					0.039
Private, employer/group	196	30.0 (25.6–34.4)	360	70.0 (65.6–74.4)		61	9.1 (6.3–11.9)	495	90.9 (88.1–93.7)	
Private, individual/non-group	83	32.3 (25.8–38.8)	159	67.7 (61.2–74.2)		37	13.1 (8.4–17.9)	205	86.9 (82.1–91.6)	
Any public	122	45.5 (39.1–51.9)	140	54.5 (48.1–60.9)		48	17.1 (11.8–22.3)	214	82.9 (77.7–88.2)	
Uninsured	46	51.7 (40.3–63.1)	49	48.3 (36.9–59.7)		17	14.8 (7.6–22.0)	78	85.2 (78.0–92.4)	
# of comorbidities[c]					0.051					0.620
0	139	32.7 (27.2–38.3)	229	67.3 (61.7–72.8)		49	10.0 (6.8–13.2)	319	90.0 (86.8–93.2)	
1	110	29.4	206	70.6		43	12.4	273	87.6	

Table 4 (continued)

	Any self-reported financial hardship					High-burden spending (total out-of-pocket > 20% of family income)				
	Yes		No			Yes		No		
	Sample $N = 477$		Sample $N = 708$			Sample $N = 163$		Sample $N = 992$		
	Population estimate = 5,922,368		Population estimate = 11,373,618			Population estimate = 2,001,021		Population estimate = 15,294,966		
	No.	Weighted %, (95% CI) [a]	No.	Weighted %, (95% CI) [a]	*P* value [b]	No.	Weighted %, (95% CI) [a]	No.	Weighted %, (95% CI) [a]	*P* value [b]
		(23.9–34.9)		(65.1–76.1)			(8.8–16.0)		(84.0–91.2)	
2+	198	39.3 (33.9–44.7)	273	60.7 (55.3–66.1)		71	12.2 (8.5–15.9)	400	87.8 (84.1–91.5)	
Time since last cancer treatment					0.038					0.233
On treatment: current or less than 1 year	141	45.5 (37.5–53.5)	130	54.5 (46.5–62.5)		44	13.3 (9.0–17.5)	227	86.7 (82.5–91)	
1 to < 5 years ago	106	29.4 (23.5–35.3)	173	70.6 (64.7–76.5)		38	10.3 (6.7–13.9)	241	89.7 (86.1–93.3)	
5 to < 10 years ago	71	31.1 (23.6–38.6)	140	68.9 (61.4–76.4)		39	15.7 (9.8–21.6)	172	84.3 (78.4–90.2)	
10+ years ago	85	33.8 (26.1–41.5)	152	66.2 (58.5–73.9)		24	8.0 (4.4–11.6)	213	92.0 (88.4–95.6)	
Never treated/unknown	44	26.6 (18.7–34.4)	113	73.4 (65.6–81.3)		18	10.6 (3.7–17.5)	139	89.4 (82.5–96.3)	
Health score (SF-12), [d]mean (SE)										
Physical component	44.2 (0.6)		48.1 (0.5)		< 0.001	41.8 (1.2)		47.4 (0.4)		< 0.001
Mental component	47.7 (0.6)		50.4 (0.4)		0.001	46.2 (1.1)		49.9 (0.3)		0.002
Health care costs, median (IQR), 2016$										
Total health expenditure [e]	5172 (1505–16,919)		3595 (1208–9794)		< 0.001	6846 (2688–20,629)		3718 (1213–10,537)		< 0.001
Total out-of-pocket [f]	663 (224–1772)		631 (186–1501)		0.001	1338 (452–3441)		597 (184–1472)		< 0.001
Premium spending [g]	3140 (1864–5251)		3547 (1781–6172)		0.558	5485 (3717–8674)		3084 (1693–5496)		< 0.001

GED general equivalency diploma, *FPL* federal poverty level, *SF-12* 12-item short form survey, *SE* standard error, *IQR* interquartile range

[a] Percentages are weighted to be nationally representative using recommended stratification, clustering, and weighting by Agency for Healthcare Research and Quality

[b] Statistically significant differences between groups were detected by Fisher exact tests, chi-square tests, *t* tests, or Wilcoxon rank sum tests, as appropriate

[c] Includes hypertension, high cholesterol, coronary heart diseases, angina, myocardial infarction, other heart disease, stroke, emphysema, and diabetes

[d] All scales are based on a scale of 0 to 100; the higher the score the better the subject's health-related quality of life in that domain

[e] Aggregate of medical expenditures in office-based medical provider, hospital outpatient, emergency room, inpatient hospital, pharmacy, home health care, and other medical expenditure

[f] Includes deductibles, coinsurance, copayments, and other cost-sharing plans

[g] Not included in total health expenditure

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