





Narrowing Insurance Disparities Among Children and Adolescents With Cancer Following the Affordable Care Act

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Abstract

Despite advances toward universal health insurance coverage for children, coverage gaps remain. Using a nationwide sample of pediatric and adolescent cancer patients from the National Cancer Database, we examined effects of the Affordable Care Act (ACA) implementation in 2014 with multinomial logistic regressions to evaluate insurance changes between 2010–2013 (pre-ACA) and 2014–2017 (post-ACA) in patients aged younger than 18 years ($n = 63\,377$). All statistical tests were 2-sided. Following the ACA, the overall percentage of Medicaid and Children's Health Insurance Program–covered patients increased (from 35.1% to 36.9%; adjusted absolute percentage change [APC] = 2.01 percentage points [ppt], 95% confidence interval [CI] = 1.31 to 2.71; $P < .001$), partly offset by declined percentage of privately insured (from 62.7% to 61.2%; adjusted APC = -1.67 ppt, 95% CI = -2.37 to -0.97 ; $P < .001$), leading to a reduction by 15% in uninsured status (from 2.2% to 1.9%; adjusted APC = -0.34 ppt, 95% CI = -0.56 to -0.12 ppt; $P = .003$). The largest declines in uninsured status were observed among Hispanic patients (by 23%; adjusted APC = -0.95 ppt, 95% CI = -1.67 to -0.23 ppt; $P = .009$) and patients residing in low-income areas (by 35%; adjusted APC = -1.22 ppt, 95% CI = -2.22 to -0.21 ppt; $P = .02$). We showed nationwide insurance gains among pediatric and adolescent cancer patients following ACA implementation, with greater gains in racial and ethnic minorities and those living in low-income areas.

Approximately 15 800 children and adolescents are diagnosed with cancer annually in the United States (1). Disparities in cancer outcomes are strongly associated with a lack of health insurance in children and adolescents (2,3). Despite advances toward universal coverage for children and adolescents, coverage gaps remain (4). By 2018, 4 million children remain uninsured (5), disproportionately higher among Hispanics, non-Hispanic Blacks, and those with low income (6).

Several provisions of the Affordable Care Act (ACA) may improve insurance coverage of children and adolescents, with mechanisms distinct from those affecting adults. First, unlike adult coverage expansion, which has not been implemented in all states (7), the child-serving provisions under the ACA guarantees nationwide Medicaid eligibility for all children and adolescents younger than 18 years living in households with income of 138% or lower of the federal poverty level (4,8). Second, the ACA enhances funding for Children's Health Insurance Program

(CHIP) (8). Third, ACA-related outreach and enrollment efforts may raise public awareness and increase enrollment of eligible, but previously uninsured, children into Medicaid and Children's Health Insurance Program (Medicaid/CHIP) (8). Moreover, the ACA provides families with private coverage options through Marketplace (a platform that offers insurance plans) (8) and extends parents' public coverage options in states that expanded Medicaid eligibility for adults aged 18 years and older (7). Coverage expansions for parents can also result in increased and more stable coverage for their children (9,10).

To date, little is known about how the ACA affects health insurance coverage of children and adolescents with cancer. The only study focusing on this population examined the 2010–2011 Medicaid expansion in 4 states (11). We provide the first nationwide estimates of changes in insurance coverage following the full ACA implementation in 2014 among pediatric and adolescent cancer patients.

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We used the National Cancer Database (NCDB), a nationwide facility-based cancer registry co-sponsored by the American Cancer Society and the American College of Surgeon's Commission on Cancer, to capture approximately 70% of all newly diagnosed cancer cases across all US states (12,13). Pediatric and adolescent patient characteristics in the NCDB are comparable to population-based cancer registries (14).

We identified all patients aged younger than 18 years newly diagnosed with a first primary cancer during 2010-2017. Only patients who were diagnosed or received part or all of their treatment at the reporting facility were included, per standard practice for analyses of the NCDB (15). Patients were categorized as having 1) no health insurance, 2) Medicaid/CHIP

coverage, or 3) private insurance (eg, employer sponsored, Marketplace) at cancer diagnosis. A small proportion (4%; n = 2792) of patients with unknown or other insurance were excluded in our analysis of the changes in uninsured status that were attributable to the change in Medicaid/CHIP or private insurance coverage, or both, following the ACA implementation. Usage of the NCDB data for this analysis was denoted as exempt on review by the institutional review board of the Morehouse School of Medicine.

Multinomial logistic regression analyses were performed to estimate changes in the likelihood that patients had no insurance, Medicaid/CHIP coverage, or private health insurance between 2010-2013 (pre-ACA) and 2014-2017 (post-ACA). Our

Table 1. Characteristics of newly diagnosed pediatric and adolescent cancer patients^{a,b}

Characteristics	Total No. (%)	Pre-ACA (2010-2013) No. (%)	Post-ACA (2014-2017) No. (%)
Total No.	63 377	31 714	31 663
Age at diagnosis, y			
0-4	21 896 (34.5)	11 269 (35.5)	10 627 (33.6)
5-9	12 860 (20.3)	6423 (20.3)	6437 (20.3)
10-14	14 740 (23.3)	7218 (22.8)	7522 (23.8)
15-17	13 881 (21.9)	6804 (21.5)	7077 (22.4)
Race and ethnicity ^c			
Hispanic	10 767 (17.4)	5360 (17.2)	5407 (17.5)
Non-Hispanic Black	7416 (12.0)	3825 (12.3)	3591 (11.6)
Non-Hispanic Other ^d	4307 (6.9)	1981 (6.4)	2326 (7.5)
Non-Hispanic White	39 545 (63.7)	19 956 (64.1)	19 589 (63.4)
Unknown	1342	592	750
Sex			
Male	33 923 (53.5)	16 948 (53.4)	16 975 (53.6)
Female	29 454 (46.5)	14 766 (46.6)	14 688 (46.4)
Zip code level median household income ^e			
Low (\leq 138% FPL) ^e	4723 (7.5)	2436 (7.7)	2287 (7.3)
Middle (139%-400% FPL) ^e	52 787 (83.7)	26 326 (83.4)	26 461 (84.0)
High ($>$ 401% FPL) ^e	5557 (8.8)	2788 (8.8)	2769 (8.8)
Unknown	310	164	146
Residence MSA status ^c			
Metropolitan	51 842 (85.1)	25 907 (85.1)	25 935 (85.0)
Non-MSA urban	8166 (13.4)	4065 (13.4)	4101 (13.4)
Non-MSA rural	938 (1.5)	470 (1.5)	468 (1.5)
Unknown	2431	1272	1159
Cancer site ^{c,f}			
Leukemias, myeloproliferative, and myelodysplastic diseases	15 946 (25.2)	8167 (25.8)	7779 (24.6)
Lymphomas and reticuloendothelial neoplasms	9103 (14.4)	4556 (14.4)	4547 (14.4)
CNS	12 001 (19.0)	6064 (19.1)	5937 (18.8)
Non-CNS solid tumors ^g	18 234 (28.8)	9102 (28.7)	9132 (28.9)
Rare tumors ^h	8009 (12.7)	3784 (11.9)	4225 (13.4)
Unknown	84	41	43

^aAuthors' analysis of the 2010-2017 National Cancer Database. ACA = Affordable Care Act; CNS = central nervous system, including intracranial and intraspinal neoplasms; FPL = federal poverty level; MSA = metropolitan statistical area.

^bA small proportion (4%; n = 2792) of patients with unknown or other insurance were excluded in our main analysis of changes in uninsured status that were attributable to the change in Medicaid and Children's Health Insurance Program or private insurance coverage, or both, following the ACA implementation. Sensitivity analyses that included patients with unknown or other insurance yielded results that were qualitatively similar in direction and significance (results available upon request).

^cPatients with missing data in the covariate were grouped into an unknown category. Percentages were calculated for the covariates after excluding the unknown category.

^dThose classified as non-Hispanic Other included a group with small sample sizes (Asian, Native American and Alaskan Native, Native Hawaiian and Other Pacific Islander, any other race and ethnicity).

^eThe cutoffs of zip code level income were chosen based on health insurance eligibility under the ACA. Specifically, the ACA expanded Medicaid eligibility to all adults with income up to 138% of FPL in participating states; thus, we used the threshold to distinguish the low-income group from other groups. Also, 400% of FPL qualifies individuals for premium tax credits on a marketplace health plan; thus, we used the threshold to distinguish the middle-income group from those with higher income.

^fCancers sites were classified using the International Classification of Childhood Cancers (<https://seer.cancer.gov/iccc/iccc-iarc-2017.html>).

^gNon-CNS solid tumors included 1) neuroblastoma and other peripheral nervous cell tumors, 2) renal tumors, 3) malignant bone tumor, 4) soft tissue and other extraosseous sarcomas, and 5) germ cell tumors, trophoblastic tumors, and neoplasms of gonads.

^hRare tumors included 1) retinoblastoma, 2) hepatic tumors, 3) other malignant epithelial neoplasms and malignant melanomas, and 4) other and unspecified malignant neoplasms.

Table 2. Changes in health insurance coverage in children and adolescents with cancer following full ACA implementation in 2014^a

Characteristics	Uninsured patients			Medicaid/CHIP-insured patients			Privately insured patients					
	Pre-ACA %	Post-ACA %	Adjusted APC ^b ppt (95% CI)	Pre-ACA %	Post-ACA %	Adjusted APC ^b ppt (95% CI)	Pre-ACA %	Post-ACA %	Adjusted APC ^b ppt (95% CI)			
			P ^c			P ^c			P ^c			
Overall (n = 63 377)	2.2	1.9	-0.34 (-0.56 to -0.12)	.003	35.1	36.9	2.01 (1.31 to 2.71)	<.001	62.7	61.2	-1.67 (-2.37 to -0.97)	<.001
By age at diagnosis, y												
0-4 (n = 21 896)	1.8	2.0	0.11 (-0.25 to 0.47)	.54	41.0	42.0	1.14 (-0.09 to 2.37)	.07	57.2	56.0	-1.25 (-2.49 to -0.02)	.046
5-9 (n = 12 860)	2.2	1.7	-0.46 (-0.94 to 0.03)	.06	36.9	39.2	2.12 (0.55 to 3.69)	.008	60.9	59.1	-1.66 (-3.24 to -0.08)	.04
10-14 (n = 14 740)	2.7	1.9	-0.86 (-1.35 to -0.36)	.001	31.8	34.4	2.71 (0.85 to 4.57)	.004	65.5	63.7	-1.85 (-3.34 to -0.37)	.02
15-17 (n = 13 881)	2.5	2.1	-0.45 (-0.94 to 0.05)	.08	26.9	29.8	2.55 (1.14 to 3.97)	<.001	70.5	68.1	-2.11 (-3.54 to -0.68)	.004
By race and ethnicity												
Hispanic (n = 10 767)	4.1	3.3	-0.95 (-1.67 to -0.23)	.009	58.1	58.3	1.04 (-0.80 to 2.87)	.27	37.8	38.4	-0.08 (-1.90 to 1.73)	.93
Non-Hispanic Black (n = 7 416)	2.8	2.2	-0.61 (-1.33 to 0.11)	.10	53.9	56.9	3.27 (1.06 to 5.47)	.004	43.3	40.9	-2.66 (-4.85 to -0.46)	.02
Non-Hispanic other (n = 4 307)	2.6	2.1	-0.52 (-1.42 to 0.38)	.26	35.4	37.6	2.33 (-0.43 to 5.10)	.10	62.0	60.4	-1.81 (-4.61 to 0.99)	.21
Non-Hispanic White (n = 39 545)	1.6	1.5	-0.13 (-0.38 to 0.11)	.28	25.3	27.3	1.96 (1.11 to 2.80)	<.001	73.1	71.2	-1.82 (-2.68 to -0.96)	<.001
By sex												
Male (n = 33 923)	2.3	2.0	-0.31 (-0.62 to -0.002)	.048	35.6	37.1	1.84 (0.89 to 2.80)	<.001	62.1	60.9	-1.53 (-2.50 to -0.57)	.002
Female (n = 29 454)	2.2	1.9	-0.37 (-0.70 to -0.05)	.03	34.5	36.7	2.21 (1.19 to 3.23)	<.001	63.3	61.4	-1.84 (-2.87 to -0.81)	<.001
By zip code level median household income ^d												
Low (<138% FPL) (n = 4 723)	3.5	2.4	-1.22 (-2.22 to -0.21)	.02	60.5	63.9	3.94 (1.23 to 6.65)	.004	36.0	33.7	-2.73 (-5.39 to -0.06)	.045
Middle (139%-400% FPL) (n = 52 787)	2.2	2.0	-0.29 (-0.54 to -0.05)	.02	35.5	37.2	1.74 (0.96 to 2.53)	<.001	62.3	60.8	-1.45 (-2.24 to -0.66)	<.001
High (>400% FPL) (n = 5 557)	1.4	1.3	-0.15 (-0.75 to 0.45)	.62	8.6	11.1	2.51 (0.01 to 4.03)	.001	90.0	87.6	-2.36 (-3.95 to -0.77)	.004
By residence MSA status												
Metropolitan (n = 51 842)	2.2	1.9	-0.36 (-0.60 to -0.11)	.004	34.2	36.1	2.15 (1.39 to 2.92)	<.001	63.6	62.0	-1.79 (-2.57 to -1.02)	<.001
Non-MSA urban (n = 8 166)	2.5	2.2	-0.26 (-0.92 to 0.40)	.44	43.2	44.8	2.14 (0.07 to 4.22)	.04	54.3	53.0	-1.88 (-3.96 to 0.20)	.08
Non-MSA rural (n = 938)	3.0	2.4	-0.85 (-2.94 to 1.24)	.43	45.5	46.6	-0.22 (-6.36 to 5.93)	.95	51.5	51.1	1.07 (-5.09 to 7.23)	.73
By cancer site												
Leukemias, myeloproliferative, and myelodysplastic diseases (n = 15 946)	2.4	1.9	-0.54 (-0.99 to -0.09)	.02	39.4	41.2	1.41 (-0.02 to 2.83)	.05	58.2	56.9	-0.87 (-2.29 to 0.56)	.24
Lymphomas and reticuloendothelial neoplasms (n = 9 103)	2.5	1.6	-0.82 (-1.42 to -0.22)	.008	31.3	33.8	2.63 (0.82 to 4.43)	.004	66.2	64.5	-1.80 (-3.63 to 0.02)	.05
CNS (n = 12 001)	2.0	2.2	0.20 (-0.31 to 0.72)	.44	34.9	37.3	2.80 (1.18 to 4.42)	.001	63.1	60.5	-3.00 (-4.63 to -1.38)	<.001
Non-CNS solid tumors ^e (n = 18 234)	2.1	2.0	-0.18 (-0.59 to 0.23)	.40	35.1	37.0	2.24 (0.94 to 3.55)	.001	62.8	61.0	-2.06 (-3.38 to -0.75)	.002
Rare tumors ^f (n = 8 009)	2.4	1.8	-0.51 (-1.14 to 0.12)	.11	30.3	31.3	1.33 (-0.55 to 3.21)	.17	67.4	66.9	-0.82 (-2.72 to 1.09)	.40

^aAuthors' analysis of the 2010-2017 National Cancer Database. ACA = Affordable Care Act; APC = absolute percentage change; CNS = central nervous system, including intracranial and intraspinal neoplasms; FPL = federal poverty level; MSA = metropolitan statistical area; ppt = percentage points.

^bTo address potential confounding, regression models also adjusted for age, sex, race and ethnicity, zip code level median household income, residence metropolitan, and statistical area status, with residence states adjusted as a random effect. The adjusted APC estimates reported in each row were from a single multinomial logistic regression model, and the number of observations for this model was noted in the first column of this table. We used the "margins" postestimation command of multinomial logistic regression model in Stata software to obtain the APC (ie, marginal effects) for each health insurance status.

^cP values were calculated from multinomial logistic regression models and reflect 2-sided test of statistical significance.

^dThe cutoffs of zip code level income were chosen based on health insurance eligibility under the ACA. Specifically, the ACA expanded Medicaid eligibility to all adults with income up to 138% of FPL in participating states; thus, we used the threshold to distinguish the low-income group from other groups. Also, 400% of FPL qualifies individuals for premium tax credits on a marketplace health plan; thus, we used the threshold to distinguish the middle-income group from those with higher income.

^eNon-CNS solid tumors included 1) neuroblastoma and other peripheral nervous cell tumors, 2) renal tumors, 3) malignant bone tumor, 4) soft tissue and other extraosseous sarcomas, and 5) germ cell tumors, trophoblastic tumors, and neoplasms of gonads.

^fRare tumors included 1) retinoblastoma, 2) hepatic tumors, 3) other malignant epithelial neoplasms and malignant melanomas, and 4) other and unspecified malignant neoplasms.

modeling approach estimated the nationwide change in patients' uninsured status following the ACA implementation in January 2014. All models adjusted for sex, race and ethnicity (abstracted from each reporting facility's medical records), age, zip code level of median household income, and rurality (Table 1). As in previous ACA studies, residence state was included as a random effect to account for within-state clustering (16-19). Consistent with prior research (20-22), results from these models were presented as marginal effects (MEs) for the post-ACA (vs pre-ACA) period. MEs were calculated at the observed values of other covariates in the model using the "margins" command in Stata Statistical Software (23). MEs were interpreted as the percentage-point difference post- vs pre-ACA in the model-adjusted likelihood of patients who had a specific health insurance status (24). Our analyses were performed for patients overall and by salient sociodemographic factors. *P* values based on *z* tests from regression models were calculated. Statistical significance was determined at .05 with 2-sided tests.

We identified 63 377 patients in the pre- ($n = 31\,714$) and post-ACA ($n = 31\,663$) periods (Table 1). Overall, the percentage of Medicaid/CHIP-covered patients increased (from 35.1% to 36.9%; adjusted absolute percentage change [APC] = 2.01 percentage points [ppt], 95% confidence interval [CI] = 1.31 to 2.71; $P < .001$), whereas the percentage of privately insured patients declined (from 62.7% to 61.2%; adjusted APC = -1.67 ppt, 95% CI = -2.37 to -0.97; $P < .001$), leading to a reduction by 15% in uninsured status (from 2.2% to 1.9%; adjusted APC = -0.34 ppt, 95% CI = -0.56 to -0.12; $P = .003$; Table 2).

When stratified by key sociodemographic factors, the change in uninsured status post-ACA varied across patient subgroups (Table 2). Specifically, the percentage of uninsured patients declined more in Hispanic patients (by 23% with adjusted APC = -0.95 ppt, 95% CI = -1.67 to -0.23; $P = .009$) and non-Hispanic Black patients (by 22% with adjusted APC = -0.61 ppt, 95% CI = -1.33 to 0.11; $P = .10$), compared with non-Hispanic White peers (by 8% with adjusted APC = -0.13 ppt, 95% CI = -0.38 to 0.11; $P = .28$). There was a reduction by 35% in uninsured status among patients residing in low-income areas (adjusted APC = -1.22 ppt, 95% CI = -2.22 to -0.21; $P = .02$) post-ACA, whereas no change was observed among those living in high-income areas (adjusted APC = -0.15 ppt, 95% CI = -0.75 to 0.45; $P = .62$). Across age groups, the largest reduction in uninsured status was observed among those aged 10-14 years (by 32% with adjusted APC = -0.86 ppt, 95% CI = -1.35 to -0.36; $P = .001$).

Following ACA implementation, the percentage of uninsured children and adolescents newly diagnosed with cancer declined by 15%, attributable to an increase in Medicaid/CHIP coverage. This finding is consistent with changes in uninsured status following the ACA among the general population (25,26). Importantly, patients living in low-income areas and Hispanic patients experienced the largest decline in uninsured status, suggesting the potential of the ACA in narrowing health-care disparities among underserved children with cancer. Across the pediatric age spectrum, a statistically significant decline was observed among adolescents aged 10-14 years, subpopulations that experienced higher uninsured rates preceding the ACA and thereby more potential opportunities for improvements.

Interestingly, although there was an increase of 2.01 percentage points in the proportion of Medicaid/CHIP-covered patients from the pre- to post-ACA periods, our results suggested that 83% (ie, 1.67 ppt divided by 2.01 ppt) of this increase was offset by a decline in private insurance, collectively contributing to a decrease of 0.34 percentage points in the proportion of uninsured. This phenomenon was termed *crowd-out* in prior

research (27,28). Parents may switch their child's coverage from private plans to Medicaid/CHIP at diagnosis if the public option offers broader benefits for children (29). Furthermore, Medicaid prevents the use of premium or cost-sharing requirements for children and adolescents younger than 18 years (4), which is particularly important for families facing high out-of-pocket costs of cancer treatment. Notably, findings from previous studies of coverage in this population have been mixed, with some suggesting worse cancer outcomes in children with public insurance than privately insured peers (2), whereas other studies did not show such disparities (30). The effects of the crowd-out phenomenon on health outcomes for children and adolescents with cancer warrant future investigation.

This study has several limitations. The cross-sectional nature of data limited our ability to infer causality. The NCDB records patients' health insurance only once; we lack data on insurance transitions during pediatric cancer treatment and survivorship, an area that merits future research (31).

We provide the first evidence on nationwide insurance gains among pediatric and adolescent cancer patients, with greater gains in racial and ethnic minority patients and those living in low-income areas, following full ACA implementation. More research is needed to monitor the ACA-associated changes in pediatric and adolescent cancer outcomes, including disease acuity at presentation, late morbidities, and mortality, as well as disparities in these outcomes (19).

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Data Availability

The data underlying this article were provided by the American College of Surgeons and accessed at the American Cancer Society by permission. The data cannot be shared publicly per the Data User Agreement. The National Cancer Database Participant User Files are available through application to investigators associated with the Commission on Cancer accredited

cancer programs (<https://www.facs.org/quality-programs/cancer/ncdb/puf>).

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