

## Childhood Cancer Survivor Study Participants' Perceptions and Understanding of the Affordable Care Act

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### ABSTRACT

#### Purpose

The Patient Protection and Affordable Care Act (ACA) established provisions intended to increase access to affordable health insurance and thus increase access to medical care and long-term surveillance for populations with pre-existing conditions. However, childhood cancer survivors' coverage priorities and familiarity with the ACA are unknown.

#### Methods

Between May 2011 and April 2012, we surveyed a randomly selected, age-stratified sample of 698 survivors and 210 siblings from the Childhood Cancer Survivor Study.

#### Results

Overall, 89.8% of survivors and 92.1% of siblings were insured. Many features of insurance coverage that survivors considered "very important" are addressed by the ACA, including increased availability of primary care (94.6%), no waiting period before coverage initiation (79.0%), and affordable premiums (88.1%). Survivors were more likely than siblings to deem primary care physician coverage and choice, protections from costs due to pre-existing conditions, and no start-up period as "very important" ( $P < .05$  for all). Only 27.3% of survivors and 26.2% of siblings reported familiarity with the ACA (12.1% of uninsured v 29.0% of insured survivors; odds ratio, 2.86; 95% CI, 1.28 to 6.36). Only 21.3% of survivors and 18.9% of siblings believed the ACA would make it more likely that they would get quality coverage. Survivors' and siblings' concerns about the ACA included increased costs, decreased access to and quality of care, and negative impact on employers and employees.

#### Conclusion

Although survivors' coverage preferences match many ACA provisions, survivors, particularly uninsured survivors, were not familiar with the ACA. Education and assistance, perhaps through cancer survivor navigation, are critically needed to ensure that survivors access coverage and benefits.

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### INTRODUCTION

Advancements in cancer therapy and supportive care have led to a growing population of childhood cancer survivors.<sup>1</sup> These survivors are at elevated lifetime risk for treatment-related late effects,<sup>2</sup> including early mortality,<sup>3</sup> subsequent neoplasms,<sup>4-6</sup> cardiac complications,<sup>7-10</sup> reproductive difficulties,<sup>11</sup> cognitive deficits,<sup>12,13</sup> liver dysfunction, and other physical<sup>14,15</sup> and psychosocial sequelae.<sup>16-19</sup> However, the full spectrum of late effects is still relatively unknown, and late effects often do not emerge until several decades after treatment.<sup>20-23</sup> Thus, ongoing medical treatment and surveillance, with access to quality health care, are critical for this population. However, previous research, conducted

in the Childhood Cancer Survivor Study (CCSS), found that adult survivors of childhood cancer, compared with siblings, had lower rates of health insurance coverage and more difficulties obtaining coverage.<sup>24</sup> In addition, adult survivors of childhood cancer were less likely than siblings to be employed, be married, and have a high household income.<sup>25-27</sup>

The Patient Protection and Affordable Care Act (ACA)<sup>28</sup> was signed into law in 2010 and is intended to increase access to affordable, quality health care, including promoting care for populations with pre-existing conditions, such as childhood cancer survivors. At the 2014 closeout of the initial ACA enrollment period in March 2014, 9.5 million uninsured people in the United States had gained coverage.<sup>29</sup> The advent of this legislation is

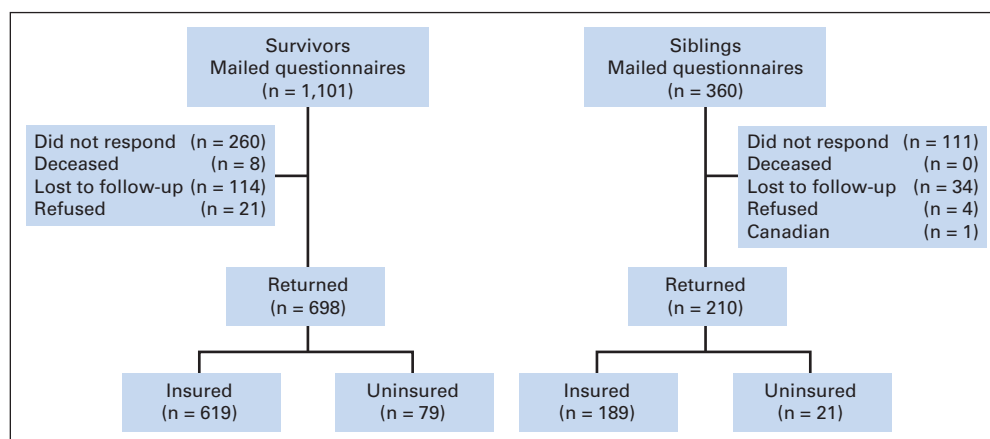


Fig 1. CONSORT diagram.

timely, because the reality of high copayments, high deductibles, and the recent declines in access to, and increased costs of, employer-sponsored insurance often leaves individuals financially encumbered.<sup>30-32</sup> Specific provisions were enacted in 2010 that could benefit childhood cancer survivors, including high-risk insurance pools for those with pre-existing conditions, expansion of insurance coverage to dependents up to age 26 years, Medicaid expansion, and regulations specifying essential health benefits, mandatory primary care visits, and preventive care coverage requirements, including annual checkups and cancer screenings.<sup>33</sup>

Because the extent of childhood cancer survivors' understanding of the ACA and coverage preferences is largely unknown, we surveyed a subset of survivors and siblings from the CCSS to examine familiarity with the ACA and other health insurance–related legislation before full implementation, concerns and hopes for the ACA, and priorities of insurance coverage.

## METHODS

### Design

Between May 2011 and April 2012, we performed a single, cross-sectional survey of a randomly selected, age-stratified sample of CCSS participants and a sibling comparison population. All procedures were approved by the institutional review boards of St Jude Children's Research Hospital and the Massachusetts General Hospital/Partners HealthCare.

### Participants

The CCSS is a multi-institutional retrospective cohort study with longitudinal follow-up that was initiated in 1994 to track the health outcomes of adult survivors of childhood cancer and compares the results with those of siblings. Eligible survivors were initially diagnosed with cancer between 1970 and 1986, were younger than 21 years old at diagnosis, and survived  $\geq 5$  years from diagnosis. The CCSS includes survivors of leukemia, lymphoma, CNS malignancy, Wilms tumor, neuroblastoma, soft tissue sarcoma, and bone cancers. The original cohort had 14,357 survivors and a cohort of randomly selected nearest-age siblings ( $n = 4,023$ ).<sup>34-36</sup> Participants were identified from the original cohort's 25 participating centers in the United States.

### Data Collection

For the current study, 1,101 survivors and 360 siblings were randomly selected from three age strata ( $< 30$ ,  $30$  to  $39$ ,  $\geq 40$  years). Surveys were mailed to selected participants and were completed either on mailed paper versions or on the Internet; instructions indicated that the survey would take approxi-

mately 15 to 20 minutes to complete. The final sample (Fig 1) included 698 completed survivor surveys and 210 sibling surveys. The survivor response rate was 63.4% (698 participants of 1,101 selected), and the sibling response rate was 58.3% (210 participants of 360 selected). The participation rate, which differs from the response rate in that known ineligible (ie, deceased, no known telephone number or address) are removed from the denominator, was 71.4% for survivors (698 participants of 978 known eligibles) and 64.4% for siblings (210 participants of 326 known eligibles).

### Measures

Survey development was informed by an initial qualitative study<sup>37</sup> and by national surveys<sup>38-42</sup>; surveys were cognitively tested with adult childhood cancer survivors treated at Massachusetts General Hospital. Based on responses to the first survey question, "Do you currently have health insurance that covers doctor and hospital care?" participants were directed to complete either an insured or uninsured version of the survey (<https://ccss.stjude.org/documents/original-cohort-questionnaires>). Current marital status, employment status, household income, and insurance characteristics were assessed. Data on other sociodemographic, cancer-related, and treatment-related factors were determined from CCSS baseline and follow-up surveys. The incidence of chronic health conditions was obtained from the most recent follow-up survey.

To provide context for levels of ACA familiarity endorsement, we queried participants about existing health insurance–related laws ("Please rate how familiar you are with the health insurance–related benefits and protections that will be available under the new health care reform law."). Participants' familiarity with the ACA, Americans with Disabilities Act (ADA), Health Insurance Portability and Accountability Act (HIPAA), Family Medical Leave Act (FMLA), and Consolidated Omnibus Budget Reconciliation Act (COBRA) was assessed on a 4-point scale from "very familiar" to "not at all familiar"; responses were subsequently dichotomized as "very/somewhat familiar" versus "not too/not at all familiar." Survey items queried participants' perceived likelihood of obtaining quality insurance coverage through the ACA ("more likely," "no change," "less likely," or "don't know"), hopefulness about the ACA's benefits/protections ("yes," "no," or "don't know"), and concerns about the ACA's benefits/protections ("yes," "no," or "don't know"). Participants rated, on a 4-point scale, the importance of insurance coverage, features, and costs; responses were subsequently dichotomized as "very important" versus "somewhat/not at all important." Two write-in questions queried participants about their concerns and hopes for the protections and benefits of the ACA.

### Statistical Analysis

All statistical analyses were performed in Stata version 12 (Stata, College Station, TX), incorporating weighting to account for the stratified sampling design so that results were representative of the age distribution in the CCSS

cohort. All *P* values are two-sided and considered significant if *P* < .05. Survivors and siblings were compared on sociodemographic and insurance characteristics, familiarity with the ACA, perceptions of the ACA, and importance of plan coverage, features, and costs using *t* tests and  $\chi^2$  analyses. Among survivors only, unadjusted analyses and multivariable logistic regression models were run to determine the effect of insurance status on familiarity with health-related legislation and the importance of health plan coverage, features, and cost, adjusting for age, sex, marital status, and presence of any chronic health condition. Content analyses were performed on participants' write-in responses to their concerns and hopes for the ACA by two coders (M.F. and E.R.P.). Major themes were identified, compared, and contrasted between survivors and siblings and insured and uninsured participants.

## RESULTS

### Participant Characteristics

Over half of survivors and siblings were female, and 93% identified as white (Table 1). The average time since diagnosis was 30.3 years (standard deviation, 4.6 years). The most common cancer diagnosis was leukemia (35.0%). Consistent with previous CCSS research,<sup>25-27</sup> when compared with siblings, survivors were less likely to be married (73.6% v 61.3%, respectively; *P* = .002), be employed (80.3% v 74.7%, respectively; *P* = .002), and have higher household incomes (*P* = .02).

### Insurance Characteristics and Perceptions of the ACA

Overall, 89.8% of survivors and 92.1% of siblings were currently insured (*P* = .31, Table 2). Survivors, compared with siblings, were significantly less likely to have employer-sponsored coverage (79.4% v 86.0%, respectively; *P* = .04) and more likely to be covered by Medicaid/state insurance (12.3% v 4.4%, respectively; *P* = .002). Only 21.3% of survivors and 18.9% of siblings reported that the ACA would make it more likely that they would get quality coverage; notably, 44.2% of survivors and 35.0% of siblings responded that they "don't know." In addition, approximately half of survivors (49.6%) and siblings (45.4%) responded "don't know" regarding concerns about the ACA benefits and protections. Only 17.0% of survivors and 18.6% of siblings felt hopeful about the benefits and protections offered by the ACA.

When comparing insured and uninsured survivors, only 9.3% of uninsured survivors, compared with 22.6% of insured survivors, believed that the ACA would make it more likely for someone with their health history to get coverage; 24.6% of uninsured survivors versus 20.7% of insured survivors believed that the ACA would make it less likely for someone with their health history to get coverage, and 56.2% of uninsured survivors versus 42.9% of insured survivors responded "don't know" (overall *P* = .04; data not shown).

### Importance of Health Plan Coverage, Features, and Cost

**Coverage.** Acute cancer-specific care and acute non-cancer-specific care were considered "very important" by more than 80% of survivors and siblings (Table 3). Inclusion of primary care was deemed "very important" by 94.6% of survivors compared with 90.4% of siblings (*P* = .04).

**Features.** A majority of survivors and siblings rated no waiting period (79.0% v 69.7%, respectively; *P* = .01) and choice of primary care physician (78.3% v 69.4%, respectively; *P* = .01) as "very important," although with significantly greater endorsement by survivors.

**Cost.** Affordable premiums were rated as "very important" by the greatest number of survivors and siblings (88.1% v 83.7%, respectively; *P* = .13). No added expenses due to pre-existing conditions were supported by most survivors (87.4%) but by fewer siblings (68.9%; *P* < .001). Low deductible was ranked as "very important" by 73.4% of survivors and 64.5% of siblings (*P* = .02).

**Comparisons between insured and uninsured survivors.** There were no differences between insured survivors and uninsured survivors in importance ratings for plan features and costs. Importance of dental coverage was the only area in which uninsured and insured survivors differed, with 79.1% of uninsured survivors versus 66.2% of insured survivors (*P* = .04) rating this coverage as "very important." These results held when we examined health plan coverage, features, and cost in multivariable logistic regression models.

### Familiarity With Health Insurance-Related Legislation

Overall, self-reported familiarity with health insurance-related laws was low and did not differ significantly between survivors and siblings (Fig 2A). Only 27.3% of survivors and 26.2% of siblings reported familiarity with the ACA, and in comparison, less than 40% of survivors and siblings reported familiarity with the long-standing ADA. Familiarity was the highest with the FMLA.

Uninsured survivors were significantly less likely than insured survivors to report familiarity with these laws (Fig 2B). Familiarity with the ACA was greater among the insured than the uninsured (29.0% v 12.1%, respectively); insured survivors were 2.86-fold (95% CI, 1.28-fold to 6.36-fold) more likely than uninsured survivors to endorse familiarity with the benefits and protections of the ACA. Insured survivors were also more than twice as likely as uninsured survivors to report familiarity with the FMLA (52.7% v 29.3%, respectively; odds ratio [OR], 2.19; 95% CI, 1.19 to 4.05), COBRA (42.6% v 22.4%, respectively; OR, 2.41; 95% CI, 1.26 to 4.60), and HIPAA (46.2% v 23.7%, respectively; OR, 2.40; 95% CI, 1.26 to 4.56).

### Concerns and Hopes About the ACA

Survivors and siblings wrote in responses to open-ended questions about concerns and hopes about the ACA (20% wrote in concerns and 12% wrote in hopes). The content of these responses did not differ between survivors and siblings. However, issues of particular salience to insured survivors and insured siblings included uncertainty about the content of insurance coverage, continuation of coverage (eg, ability to choose their physician of choice), and costs associated with mandated coverage (Table 4).

Survivors' and siblings' most frequently expressed concern about the ACA was its effect on costs, through perceived high costs of coverage for individuals with pre-existing conditions, increased premiums, and out-of-pocket costs. Survivors and siblings were also concerned about decreased access to coverage, comprehensiveness of coverage, quality of insurance, and restrictions of benefits. Access to care concerns focused on the availability of physicians, increased wait time, and insufficient care for those who were in greatest need of care. Concerns also included anticipated decreases in quality of care as a result of increasing numbers of people with insurance, which was described as "socialized medicine" and "rationed care." Survivors and siblings expressed concern over the government's control in dictating who would get what type of care. Lastly, there were concerns that the ACA requirement to provide employee coverage would cause employers to go out of business, cut coverage, or cut employees.

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**Table 1.** Demographics and Cancer-Related Characteristics of Survivors of Childhood Cancer and Siblings

Characteristic	Survivors (n = 698)		Siblings (n = 210)		P†
	No.	Weighted %*	No.	Weighted %*	
Age at survey, years					.06
22-29	214	11.3	61	13.5	
30-39	228	42.3	68	33.6	
40-62	256	46.4	81	52.9	
Sex					.11
Male	314	45.5	82	38.9	
Female	384	54.5	128	61.1	
Race/ethnicity					.96
White, non-Hispanic	646	93.5	185	93.5	
Black, non-Hispanic	14	1.7	4	1.9	
Hispanic/Latino	24	3.0	6	2.4	
Other	12	1.8	5	2.2	
Education					.40
Less than high school through high school graduate	98	14.1	19	11.7	
Some postgraduate college	179	26.8	51	23.3	
Completed college	352	59.1	122	65.0	
Marital status					.002
Married, living as married	393	61.3	141	73.6	
Single, never married	240	28.5	49	16.1	
Divorced or separated	59	10.2	19	10.3	
Employment status					.002
Employed (full time or part time)	510	74.7	163	80.3	
Unemployed and looking for work	44	6.1	8	3.0	
Unable to work due to illness or disability	66	9.3	4	2.2	
Other	69	9.9	32	14.5	
Household income					.02
< \$20,000	91	12.0	12	5.2	
\$20,000-\$39,999	106	14.9	24	10.7	
\$40,000-\$59,999	104	15.8	35	16.9	
\$60,000-\$79,999	95	14.8	32	16.1	
> \$80,000	240	38.3	90	48.7	
Don't know	36	4.2	8	2.4	
Cancer diagnosis					
Leukemia	255	35.0			
CNS	104	14.9			
Hodgkin lymphoma	71	12.9			
Neuroblastoma	67	6.1			
Wilms (kidney) tumor	66	8.1			
Soft tissue sarcoma	51	8.3			
Bone	45	8.1			
Non-Hodgkin lymphoma	39	6.7			
Age at diagnosis, years					
0-5	404	46.4			
6-10	104	19.1			
11-15	109	19.8			
16-20	81	14.7			
Time since diagnosis, years					
Mean		30.3			
Standard deviation		4.6			
Recurrence of primary malignancy	611	88.1			
No	87	11.9			
Yes					
Subsequent cancer	668	94.9			
No	30	5.1			
Yes					
Prevalence of chronic health condition					< .001
None	111	15.1	68	32.3	
Mild to moderate	319	45.1	114	52.0	
Severe to life threatening	268	39.8	28	15.7	

NOTE. The total numbers in the table might not add up to 698 for survivors or 210 for siblings because of missing data.  
 \*Percentages are weighted to reflect the population age distribution of the full Childhood Cancer Survivor Study cohort.  
 †P value comparing survivors and siblings.

**Table 2.** Health Insurance Coverage and ACA Perceptions of Survivors of Childhood Cancer and Siblings

Factor	Survivors (n = 698)		Siblings (n = 210)		P†
	No.	Weighted %*	No.	Weighted %*	
Health insurance					.311
Insured	619	89.8	189	92.1	
Uninsured	79	10.2	21	7.9	
Policy owner for primary insurance plan‡					.34
Self	486	71.0	141	67.5	
Spouse	154	24.5	55	29.9	
Parent	36	3.6	8	2.1	
Other/don't know	7	< 1	1	< 1	
Types of insurance for uninsured (can select more than one)‡					
Employer sponsored/military	510	79.4	172	86.0	.04
Medicaid/state	94	12.3	10	4.4	.002
Individual	54	7.5	21	8.9	.52
Medicare	56	7.4	2	< 1	< .001
Don't know	6	0.5	1	< 1	.94
Likelihood of obtaining quality coverage under the ACA					< .001
Don't know	306	44.2	74	35.0	
More likely	144	21.3	39	18.9	
Less likely	134	21.0	33	17.1	
No change	95	13.5	54	29.0	
Concerns about health insurance benefits/protections under the ACA					.27
Don't know	336	49.6	96	45.4	
No	188	27.7	52	26.0	
Yes	146	22.7	53	28.6	
Feel hopeful about health insurance benefits/protections under the ACA					.05
Don't know	346	50.0	84	39.7	
No	212	33.0	80	41.7	
Yes	115	17.0	40	18.6	

NOTE. The total numbers in the table might not add up to 698 for survivors or 210 for siblings because of missing data.

Abbreviation: ACA, Patient Protection and Affordable Care Act.

\*Percentages are weighted to reflect the population age distribution of the full Childhood Cancer Survivor Study cohort.

†P value comparing survivors and siblings.

‡For uninsured participants, the most recent insurance coverage was used.

However, there was a cautious sense of hopefulness for quality, yet affordable, care, with an acknowledgment that the ACA was not the “perfect solution.” Improved insurance access for more Americans was the most frequently expressed hope for the ACA. In particular, survivors were hopeful that they could receive coverage and thus alleviate “job lock” fears (ie, feeling constrained in job mobility as a result of needed employer-sponsored insurance).

## DISCUSSION

In 2010, the US government passed the ACA to expand access to affordable care to all citizens. Because one goal of the ACA was to increase access to needed medical care, including surveillance, it is critical to ascertain cancer survivors' perceptions of this legislation. Thus, 1 year after its enactment in 2011, we conducted the first national examination of childhood cancer survivors' desired coverage features, understanding of the ACA and other insurance-related laws, and hopes and concerns.

Of importance is that features of insurance coverage that survivors consider to be “very important” are indeed addressed by the ACA, such as prohibiting waiting periods and coverage limits. Features such as acute, non-cancer-specific care are understandably prioritized by survivors, given the high incidence of chronic health conditions (73%)

for childhood cancer survivors 30 years after diagnosis.<sup>20,22</sup> Factors that survivors were differentially more likely than siblings to deem “very important,” such as primary care coverage and choice and protections from additional costs due to pre-existing conditions, are also aligned with the ACA legislation. Furthermore, the ACA requires coverage with no out-of-pocket costs for essential health benefits that have an A or B rating by the US Preventive Services Task Force (USPSTF); however, USPSTF guidelines are not based on survivor-specific preventive guidelines and, as such, may not cover an individual's screening recommendations from the Children's Oncology Group guidelines that are tailored to one's cancer or cancer treatment.<sup>43</sup>

One year after implementation of the ACA and its multiple provisions that could benefit childhood cancer survivors, survivors endorsed low levels of familiarity with the ACA, mirroring that of the general population at the time.<sup>44</sup> Although the current survey occurred during the roll out of key ACA provisions such as expanded coverage for young adults, a time of heightened attention and publicity, only a quarter of childhood cancer survivors and siblings were familiar with the ACA. Indeed, even for the long-established ADA, which protects individuals like survivors from discrimination, only a third of survivors and siblings endorsed familiarity. Survivors' lack of familiarity with these laws was consistent with our recent qualitative

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**Table 3.** Coverage Priorities: Plan Coverage, Features, and Cost Ranked As “Very Important”

Factor	Survivors v Siblings					Survivors by Insurance Status							
	Survivors		Siblings		P‡	Insured Survivors		Uninsured Survivors		P§	Multivariable Odds Ratios: Insured v Uninsured Survivors (reference)*		
	No.	Weighted %†	No.	Weighted %†		No.	Weighted %†	No.	Weighted %†		Odds Ratio	95% CI	P
<b>Plan coverage</b>													
Primary care	639	94.6	182	90.4	.04	569	94.9	70	91.8	.33	1.59	0.52 to 4.81	.41
Acute, cancer-specific care	579	86.0	156	80.9	.09	517	86.3	62	83.3	.53	1.43	0.66 to 3.06	.36
Acute, non-cancer-specific care	539	81.3	158	80.4	.80	485	82.0	54	74.8	.17	1.80	0.94 to 3.46	.08
Dental care	454	67.5	128	63.7	.34	395	66.2	59	79.1	.04	0.52	0.26 to 1.02	.06
Vision care	408	60.7	102	49.3	.01	359	60.1	49	65.3	.44	0.86	0.48 to 1.54	.62
Mental health care	271	40.2	73	40.5	.96	239	39.4	32	47.7	.22	0.82	0.47 to 1.43	.49
<b>Plan features</b>													
No waiting period before coverage begins	533	79.0	140	69.7	.01	471	78.6	62	82.0	.55	1.00	0.48 to 2.06	.99
Choice of primary care physician	518	78.3	136	69.4	.01	465	78.8	53	74.2	.41	1.29	0.67 to 2.49	.45
No coverage limits (lifetime or annual)	484	72.3	135	67.2	.19	430	72.1	54	74.0	.76	0.95	0.50 to 1.82	.88
Ability to self-refer	376	56.7	102	51.1	.19	333	55.8	43	64.6	.19	0.74	0.41 to 1.32	.30
<b>Plan cost</b>													
Affordable premiums	594	88.1	169	83.7	.13	523	87.4	71	94.2	.15	0.48	0.14 to 1.62	.24
No added expense due to pre-existing conditions	590	87.4	141	68.9	< .001	523	87.2	67	88.8	.73	1.00	0.42 to 2.42	.99
Low deductible	496	73.4	135	64.5	.02	438	72.6	58	80.3	.20	0.68	0.35 to 1.34	.26
Low co-pay	497	72.9	136	66.3	.09	437	72.2	60	79.6	.22	0.69	0.34 to 1.36	.28

\*Models adjusted for current age, sex, marital status, and chronic disease.

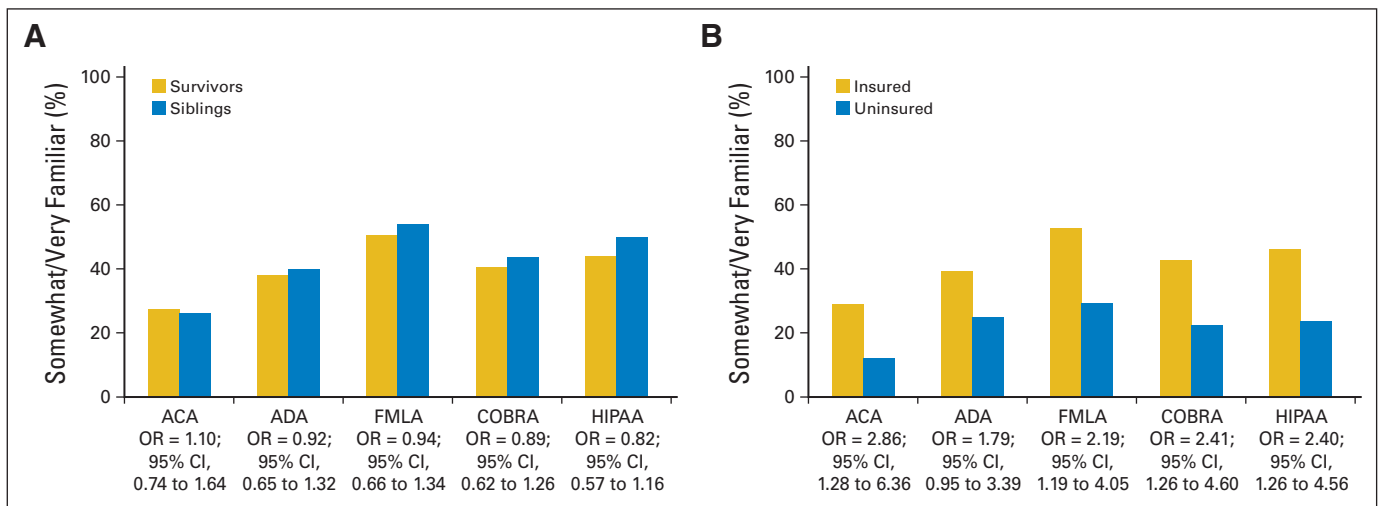
†Percentages are weighted to reflect the population age distribution of the full Childhood Cancer Survivor Study cohort.

‡P value calculated for survivors and siblings, comparing those who indicate these features as “very important” with those rating the features as “somewhat important” to “not at all important.”

§P value comparing insured survivors with uninsured survivors.

findings, in which almost all childhood cancer survivors expressed unfamiliarity with health insurance–related legislation.<sup>37</sup> This suggests that survivors may not access, or understand, ACA provisions intended for them now that health insurance exchanges are available. Of great concern is that, among survivors, the uninsured were

less likely to be familiar with this legislation, indicating that the most vulnerable could be the least likely to use these protections. This is consistent with a recent Kaiser poll that revealed that the uninsured reported low familiarity and less favorability for the ACA than the population at large.<sup>45</sup>



**Fig 2.** Familiarity of (A) survivors of childhood cancer and their siblings and of (B) insured and uninsured survivors with health insurance–related legislation. Multivariable logistic regressions adjusted for current age, sex, marital status, and chronic disease. Models comparing survivors and siblings were also adjusted for insurance status. ACA, Patient Protection and Affordable Care Act; ADA, Americans with Disabilities Act; COBRA, Consolidated Omnibus Budget Reconciliation Act; FMLA, Family Medical Leave Act; HIPAA, Health Insurance Portability and Accountability Act; OR, odds ratio.

**Table 4.** Qualitative Responses: Survivors' and Siblings' Concerns and Hopes About the New Health Care Reform Law

Concerns	Hopes
Cost of coverage	
Cost increase on an individual level	Cost savings on an individual level (affordability)
Affordability	
Increased premiums	
Increase to those with pre-existing conditions	
Expense to the country/those who pay for insurance	Cost savings to the country
Insurance coverage	
Decreased access to insurance coverage	Increased access to insurance coverage
Uncertain who will qualify	More people will have access
Exclusions for those with pre-existing conditions	No exclusions for those with pre-existing conditions
	Decreased reliance on employment/decreased job lock
Reduced comprehensiveness of coverage	Improved comprehensiveness of coverage
Cuts in benefits	Expansion of benefits
Decreased quality of coverage	Quality with affordability
Decreased continuity of coverage	Longer coverage for dependents
Uncertainty about content of coverage	
Changes to Medicaid	
Changes to Medicare	
Changes to long-term disability	
Access to care	
Harder to access medical services	Improved access to medical care for more people
Dearth of care as a result of increase in number of insured	
Unable to access and retain physicians of choice/quality	
Quality of care	
Decrease in quality of medical services	Quality while still being affordable
Systems	
Government involvement in health care/individual mandate	Improve regulation/identify causes of high medical costs
Employment	
Negative impact on employers and employees	
Cuts in employer-sponsored coverage	

Given the low levels of familiarity with the ACA, it is not surprising that survivors' impressions of the ACA were unfavorable and uninformed. It is possible that childhood cancer survivors may be influenced by political and media messages regarding the ACA since its passage. It is critical to underscore that almost half of survivors selected the response "don't know" when asked about their concerns, hopes, and expectations for the ACA. Only one in five survivors and siblings felt that the ACA would make it more likely that they would get quality coverage or felt hopeful about the benefits and protections offered under the ACA. This is lower favorability than was reported in Kaiser polls conducted from 2011 to 2012,<sup>46</sup> in which one third of Americans rated the ACA favorably. The Kaiser results indicated that those with higher scores of knowledge about the ACA were more likely

to believe that they would be better off because of the ACA. Accordingly, given the lack of familiarity with the ACA, our study revealed a dearth of positive expectations written in by survivors and siblings.

Open-ended responses illustrated survivors' and siblings' shared concerns about the ACA's effect on costs, coverage content, access and quality of care, and employment. Insured participants, in particular, expressed concerns about the cost, access, and continuity of care. Past findings showed that approximately one in three childhood cancer survivors have had difficulties obtaining coverage<sup>24</sup>; however, the ACA may help mitigate the burden of costs reported by survivors through its requirement that companies undergo a review process before issuing rate increases, expanded Medicaid eligibility, and income-based subsidies among those obtaining coverage through insurance exchanges. In addition, survivors' fears of loss of coverage can be allayed by the ACA provision prohibiting policy cancellations when someone gets sick, as well as the requirement, as of 2014, that companies provide coverage, without increased premiums, to individuals with pre-existing conditions. However, although the ACA could increase the number of survivors covered, complying with the individual mandate could remain financially prohibitive for some who choose to remain uninsured. Past research indicates that uninsured survivors minimize and/or avoid their need for health care<sup>37</sup>; thus, it is possible that these survivors may choose to forgo care even with expanded coverage options, leaving themselves vulnerable to financial penalties.

Although there are many potential benefits of the ACA for survivors, there are also many uncertainties and concerns of which survivors must be made aware. For example, coverage mandates may make premiums go up, and plans in the exchanges may have high levels of cost sharing to offer more affordable premiums,<sup>47,48</sup> which would be difficult for survivors needing a lot of medical services. Plans in exchanges may also include narrow networks that limit where members can get care. With the mandate, people may choose these plans because they have lower premiums, but survivors might not be able to see the specialists and seek care at the hospitals they want.

Improved access and affordability were rated by survivors as "very important" but were also written about as a source of both hope and concern. Hopeful sentiments were less frequent and were expressed cautiously. This expressed tone was consistent with previous qualitative work we conducted, in which low coverage expectations were shared among CCSS participants, which belied fears about health and coverage stability.<sup>37</sup> The ACA seeks to improve access and affordability through state-run insurance exchanges, Medicaid expansion (although only half of states currently have opted to expand eligibility), extended age of parental coverage, and no denial because of pre-existing condition or coverage limits. Furthermore, the ACA targets improvements on access to and continuity of care for populations with pre-existing conditions, including cancer survivors, through increased funding for community health centers, support for community-based collaborative care networks and medical homes, creating requirements for culturally and linguistically competent care, and covering clinical trial costs.<sup>49</sup>

Although drawn from an established national data set of childhood survivors, this analysis has noteworthy limitations. Data relating to health insurance status are self-reported from a cohort of survivors with limited numbers of racial and ethnic minorities treated at tertiary cancer centers. Siblings of childhood survivors may not be representative of the national population; it is reasonable to assume that siblings of survivors have a heightened awareness of the importance of

access to quality health care and coverage. Open-ended responses about concerns and hopes regarding the ACA were only completed by some survey respondents. Finally, we conducted the survey before the launch of the health insurance exchanges in the fall of 2013; thus, survivors' and siblings' familiarity with the ACA may be higher since this new provision was enacted.

Although survivors' health care coverage priorities are aligned in many important aspects with the ACA, we found a significant lack of understanding about, and low hopefulness for, the ACA. If assumptions can be drawn based on the low level of familiarity with the long-standing ADA and other insurance protections, this foreshadows insurance underutilization, which underscores the need to educate cancer survivors and facilitate their access to insurance coverage. For survivors to benefit from ACA provisions, it is critical that clinicians, hospitals, community-based organizations, and survivor advocacy groups encourage and facilitate utilization of these benefits. In addition, survivor navigators, who may assist survivors to overcome barriers to quality medical care and facilitate access to survivorship care and services,<sup>50</sup> may play a critical role. Furthermore, it is recommended that childhood survivors be surveyed in the future to see if their familiarity with the ACA, concerns and hopes about implementation of the ACA, and coverage priorities have changed. To determine whether the ACA was successful at improving access to quality health insurance coverage and its effects on survivors' perceived quality of

coverage and care, childhood survivors' utilization of the ACA and care services should be examined, in particular including an assessment of survivor characteristics, such as age and region, associated with ACA utilization.

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**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

**Childhood Cancer Survivor Study Participants' Perceptions and Understanding of the Affordable Care Act**

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