

Childhood Cancer Survivors' Familiarity With and Opinions of the Patient Protection and Affordable Care Act

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Abstract

Purpose: The Patient Protection and Affordable Care Act (ACA) offers avenues to increase insurance options and access to care; however, it is unknown whether populations with pre-existing conditions, such as cancer survivors, will benefit from the expanded coverage options. We explored childhood cancer survivors' familiarity with and opinion of the ACA to understand how survivors' insurance coverage may be affected.

Materials and Methods: From April to July 2012 we conducted in-depth, semistructured telephone interviews with 53 adult survivors recruited from the Utah Cancer SEER Registry. Participants were randomly selected from sex, age, and rural/urban strata and were younger than 21 years at time of diagnosis. Interviews were recorded, transcribed, and analyzed with

NVivo 9 by two coders ($\kappa = 0.94$). We report on the 49 participants who had heard of the ACA.

Results: Most survivors were unaware of ACA provisions beyond the insurance mandate. Few knew about coverage for children up to age 26 or pre-existing insurance options. Although one third believed the ACA could potentially benefit them via expanded insurance coverage, many were concerned that the ACA would lead to rising health care costs and decreasing quality of care. Survivors had concerns specific to their cancer history, including fears of future health care rationing if they developed subsequent health problems.

Conclusion: Childhood cancer survivors have a low level of familiarity with the ACA and are unaware of how it may affect them given their cancer history. These survivors require targeted education to increase knowledge about the ACA.

Introduction

Childhood cancer survivors are a growing population in the United States, with more than 328,000 survivors as of 2005.¹ The 5-year survival rate for childhood cancer is 80%,² yet approximately 40% of survivors experience at least one life-threatening health problem.^{3,4} Historically, the high cost of health insurance has limited health care access for some childhood cancer survivors.^{5,6} Moreover, the late effects experienced by many survivors may inhibit their ability to work and thereby access employer-sponsored insurance.⁵

The 2010 Patient Protection and Affordable Care Act (ACA) provides health insurance options and protections for cancer survivors.^{6,7} The ACA offers Pre-existing Conditions Insurance Plans (PCIPs) to provide insurance coverage for uninsured adults in the interim before insurance exchanges are launched in late 2013.⁶ Consumer protections such as premium oversight and insurance rescission prohibitions may help survivors with high medical costs. Other provisions include eliminating lifetime coverage limits, capping out-of-pocket expenses, and offering free preventive care.^{8,9} Furthermore, the Medicaid expansion should increase insurance options for some low-income survivors.

Despite the expanded insurance options under the ACA, political debate on this legislation has led to divided public opinion.¹⁰ As of March 2012, 59% of respondents in a national poll felt they lacked adequate information to understand how the law would affect them, and 35% thought the ACA had

provisions (eg, death panels) that are not included in the legislation.¹¹ Misinformation about the law may affect familiarity with the ACA among populations who could most benefit, such as cancer survivors, potentially influencing their ability to access insurance options under the ACA. Yet, no studies have assessed survivors' awareness or opinion of the ACA.

In this study, we interviewed 53 adult survivors of childhood cancer diagnosed in Utah to explore their familiarity with the ACA and their opinion regarding its potential impact. Because childhood cancer survivors are a high-risk population who could benefit substantially from the ACA, qualitative data can provide important insight for educational targets by identifying areas of low awareness of ACA provisions. We report on themes related to survivors' familiarity with the ACA, including their knowledge of specific ACA provisions such as the individual mandate. In addition, we describe survivors' opinions regarding the impact they believe the ACA will have on their health insurance coverage and access to health care.

Materials and Methods

This study was conducted as part of a larger study examining health care, health insurance, employment, and educational outcomes of adult childhood cancer survivors. For the current report, we focused on questions related to knowledge, perceptions, and attitudes about anticipated effects of the ACA. All materials were approved by the Institutional Review Board at the University of Utah.

Participants and Recruitment

Potential participants were identified by the Utah Cancer Registry, a population-based registry of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program. Eligible patients were diagnosed at age ≤ 21 years, from January 1, 1973, to December 31, 2009. On the basis of the eligibility criteria of the larger study, we limited participants to those born in Utah, currently age ≥ 18 years, and alive at the time of study contact. We included all diagnoses who met International Childhood Cancer Classification system criteria.¹² Nonmelanoma skin cancers and in situ cancers were excluded.

There were 2,686 eligible participants. To obtain a geographically diverse sample with adequate numbers by sex and age, the Utah Cancer Registry sent letters to 150 potential participants randomly selected from sex, age (18 to 29, 30 to 45, and 46 to 60 years), and rural/urban county at diagnosis strata. Of these, 70 had outdated contact information and could not be reached after three attempts, and three were out of the country or were disqualified as a result of participation in the pilot study. This left 77 (51%) potential participants. Of these, 14 refused and 63 agreed to participate, for a cooperation rate of 82%. Participants did not differ on age, sex, or diagnosis from those who did not agree to participate or were unreachable.

Data Collection and Analysis

To create our semistructured interview guide, we first developed a list of questions and recommended probes relevant to our topics of interest, which were pilot tested with five survivors recruited from the Huntsman Cancer Hospital Pediatric Late Effects Clinic (Salt Lake City, UT). We modified the questions on the basis of pilot participant feedback, resulting in a final survey with eight domains, including closed and open-ended questions. Informed consent was obtained by two members of the research team (A.C.K. and E.L.W.) who completed telephone interviews from April through July 2012. Interviews lasted 30 to 45 minutes and were recorded and transcribed. Participants received a modest incentive (\$20 gift card).

Content analysis of the interviews was performed by two members of the research team (A.C.K. and E.L.W.) using NVivo 9.¹³ The two analysts independently read the interviews and developed a list of descriptive codes, which they revised through discussion. Recruitment was finalized at 53 interviews, when thematic saturation occurred (the point at which no new themes emerged).¹⁴ E.L.W. coded all 53 interviews, and A.C.K. coded 10 interviews. Inter-rater reliability was high ($\kappa = 0.94$), so the decision was made not to double code further. Discrepancies were resolved by coder discussion.

The current analyses focus on the following questions from one domain: (1) whether participants had heard of the ACA (prompted as "health insurance reform" or "Obamacare"), (2) what they could describe or knew about the ACA, (3) their opinion of the ACA, and (4) whether they thought the ACA could affect them as a cancer survivor in good (ie, increased insurance access) or bad (ie, increased cost) ways.

From these four questions, three themes emerged: (1) awareness of the ACA, (2) potential ACA benefits, and (3) concerns

about the ACA. Within these main themes, we identified salient subthemes and, as relevant, describe differences between insured and uninsured survivors. Our results focus on the 49 (92.5%) participants who had heard of the ACA.

Results

Sample Characteristics

The mean age at interview was 39.1 years (SD = 11.0). As shown in Table 1, participants were primarily female (53.1%). The most common diagnosis was lymphoma (24.5%). A total of 87.7% were insured, and 12.2% were uninsured. Table 2 displays the number and percentage of participants reporting each theme.

Awareness

Survivors appear confused and uninformed about the ACA. Approximately half (51.0%) felt frustrated or confused by the ACA, as illustrated by one man who said, "[The ACA is] a mess and confusing. I don't even know what's really taken effect yet." Although participants generally knew the ACA expands insurance options, several (36.7%) expressed feeling uninformed about the ACA. Typical quotes included, "I have heard of [the ACA], I don't really know a whole lot about it," and "I don't know how to explain [the ACA]. I know everybody has to have insurance."

Familiarity with ACA provisions. Twenty-eight participants described the insurance mandate (57.1%). Of these, only four (8.2%) expressed concerns about financial penalties (eg, tax) for not having insurance. Seven survivors (14.3%) mentioned that the ACA allows dependents to stay on their parents' insurance up to age 26; three knew of this from personal experience. One young woman stated, "If I wouldn't have had that option [to stay on my parents' insurance]... I wouldn't be able to go to school because I'd [have] to work full-time to get insurance, which probably wouldn't be as good as the insurance my parents have, and we would be in a lot of debt."

Six survivors (12.2%) knew that the ACA offered pre-existing conditions insurance options and protections. These participants felt more secure about their future health insurance coverage, knowing they would not be denied coverage based on their previous cancer. One man stated, "A good aspect would be the law prohibiting denying pre-existing conditions... if I ever left my job and I wanted to be self-employed and had to buy my own insurance, the insurance company couldn't turn me down on account of the Wilms tumor history."

Of the eight uninsured survivors, five (62.5%) described ongoing problems with getting insurance coverage. With the exception of the mandate and dependent coverage, none of these survivors were familiar with ACA options for the uninsured, such as PCIPs.

Benefits

Satisfaction with the ACA. Eighteen survivors (36.7%) were satisfied with the ACA because they believed it would increase

Table 1. Participant Characteristics (N = 49)

Characteristic	No.	%
Age at interview, years		
18-29	13	26.6
30-45	18	36.7
46-60	18	36.7
Age at diagnosis, years		
0-4	10	20.4
5-9	6	12.3
10-15	10	20.4
16-20	23	46.9
Sex		
Male	23	46.9
Female	26	53.1
Race/ethnicity		
White, not Hispanic/Latino	46	93.9
Hispanic/Latino	3	6.1
Cancer diagnosis		
Lymphoma	12	24.5
Leukemia	9	18.4
Gonad/germ cell	8	16.3
Sarcoma	6	12.2
Thyroid	5	10.2
Other	9	18.4
Education		
High school or less	8	16.3
Some college/technical school	26	53.1
College graduate or more	15	30.6
Insurance		
Uninsured	6	12.2
Insured	43	87.7
Private	40	93.0
Public*	3	7.5
Rural/urban†		
Rural	24	49.0
Urban	25	51.0

* Medicaid, n = 1 and Medicare, n = 2.

† Rural: living in a county with < 75% of population in an urban area (population ≥ 2500).

their access to health care and insurance coverage. Of these survivors, 15 (83%) were currently insured, 11 (73.3%) of whom had previous experience being denied insurance as a result of their cancer history or faced high costs when buying individual insurance. One insured woman with a history of work-related disability had been denied Medicaid in the past: “I think [the ACA] would work for people like me... Watching what I’ve been through, trying to get help from Medicaid... [With the ACA] it would be a lot easier and you wouldn’t be stress on the people that’s trying to help you like my mom or my family.”

Ten survivors (20.4%) felt the ACA was not a perfect solution, but that improvements in health insurance were necessary. “[The ACA] is as good of a compromise as we’re likely to get... I

Table 2. Themes (N = 49)

Theme	No.	(%)
Awareness		
Confused and uninformed		
Confused/frustrated	25	51.0
Uninformed	18	36.7
Familiarity		
Insurance mandate	28	57.1
Dependent coverage	7	14.3
Pre-existing conditions insurance/protections	6	12.2
Benefits		
Satisfaction		
Personal access to care/insurance	18	36.7
Insurance access needed improvement	10	20.4
Disconnect between survivor status and ACA benefits	40	81.6
Concerns		
Financial burden	18	36.7
Government involvement	14	28.6
Access/quality	13	26.5
Rationing	7	14.3

Abbreviation: ACA, Affordable Care Act.

think this really is the most realistic way to get people access to care who don’t currently have it,” was one man’s perspective.

Disconnect between survivor status and ACA benefits. The idea that the ACA could improve access to insurance benefits and protections for cancer survivors had not occurred to most survivors (81.6%). One woman said, “It’s been so long [since my diagnosis], I’ve never really looked at [the ACA] from that angle.” These survivors did not think the law could benefit them because they did not perceive themselves to be different as a result of their cancer history. One man said, “Honestly, as a cancer survivor [the ACA] hasn’t made me any different than my wife, who’s not a cancer survivor. We’re not dealing with any of the cancer issues anymore.”

Concerns

Financial burden. Increased health care costs resulting from the ACA were the most common concern (36.7%), primarily for survivors who were currently insured. Of these 18 survivors, 11 (61.1%) attributed high out-of-pocket costs to the ACA. Common quotes included, “...It seems like it’s costing me more and more to take care of myself. . . that affordable care is not very affordable,” and “I imagine there are people [the ACA] will help, but right now my experience with it is it’s costing me more.” Ten survivors (20.4%) who were not worried about costs also felt the expanded options for the uninsured placed them at financial risk. One woman said, “I’m kind of on the border of being able to take care of myself. So I’m not really excited about the idea of being forced to pay for somebody else’s health care.”

Government involvement. Fourteen survivors (28.6%) expressed frustration regarding government involvement in health

care, because they felt the ACA was based on politics rather than consumer needs. One exemplar quote was, "Most of us feel that we are just irritated with our government, because it decides more about politics than what is right for the country, for the people." Eight (57.1%) of these 14 survivors questioned the constitutionality of the individual mandate, because they felt having insurance should be a personal choice. Six (42.9%) were concerned that government involvement would lead to more expensive health care; as one said, "I think that the government should get out of health insurance. If the government is in it, it costs you twice as much."

Health care access and quality. Thirteen survivors (26.5%) worried about health care access and quality under the ACA. Of these, four (30.8%) had a recent second cancer or felt their original cancer was particularly aggressive. These individuals were especially concerned about access to specialty providers and waiting periods for treatment. One woman stated her concern as, "...If I had another malignant melanoma...if I don't have the XYZ symptoms and I don't fall into this category then I'll be put on a waiting list [for treatment]." She later added, "With malignant melanoma it's a very fast growing cancer, so time is extremely important. I think that if [the ACA] became law...it would really affect my outcome."

Health care rationing as a result of cancer history. Seven survivors (14.3%) felt their cancer history placed them at risk for health care rationing under the ACA. These survivors worried they would be "passed up [for treatment] based on the needs of others" if their cancer returned or they had a new cancer. The idea that the government, medical institution, or health insurer would make their treatment decisions was a primary concern. One man put this in the context of a cancer relapse, saying, "I hate the thought of somebody else making the determination of whether I'm treatable or not. That scares me to death...I want that to be my decision and my decision only."

Discussion

The ACA offers health insurance options for individuals with pre-existing conditions and protections for those who are currently insured; however, the long-term feasibility of many of its provisions are unknown.⁶ Our interviews with Utah childhood cancer survivors generated themes that highlight potential challenges as the ACA is implemented. Although most survivors were aware that the ACA provides avenues for obtaining insurance coverage, survivors were confused about the ACA; felt skeptical about government involvement in health care; and, similar to the general population, knew little about ACA provisions.¹⁵ Some survivors expressed fear about their access to health care under the ACA and apprehension about health care rationing. Moreover, several felt the ACA had nothing to offer them as a survivor of cancer.

Although the long-term implications of the ACA are unknown, the legislation may help eliminate some of the care disparities for cancer survivors by providing several ways for uninsured survivors to obtain coverage.¹⁶ In our sample, most uninsured survivors had been without insurance for years but

were unfamiliar with insurance options offered under the ACA. Tailored education on the personal relevance of the ACA to uninsured survivors could reduce their confusion about the ACA and increase their awareness of possible insurance options, such as Medicaid. Navigators, which will be required in insurance exchanges,¹⁷ offer one important avenue for assisting low-income or uninsured survivors with enrolling in and purchasing subsidized health insurance.

However, as many elements of the ACA are in development, the full impact of this legislation on uninsured cancer survivors and those with high medical costs is unclear. Thus far, nationwide enrollment in PCIPs has been lower than expected.^{18,19} As the exchanges roll out in late 2013, the insurance requirement will hopefully incorporate healthier individuals, spreading risk and reducing insurance costs for high-risk populations.¹⁷ Also, as of May 2013, only 23 states (including Washington, DC) were moving forward on the optional Medicaid expansion.²⁰ Thus, some of the lowest income cancer survivors, who do not qualify for subsidized insurance under the exchanges, may still be unable to afford insurance.^{21,22} Furthermore, essential preventive services coverage mandated by the ACA does not explicitly include coverage of cancer-specific follow-up services or screenings for second cancers or other diseases,^{6,17} meaning the cost and access concerns described by our sample are not unwarranted.

Provisions in the ACA, such as eliminating lifetime coverage limits, appeals processes for coverage denial, and restraints on insurance rescission,¹⁷ should provide insurance protection for cancer survivors. However, many participants were unaware of ACA provisions beyond the individual insurance mandate. Several survivors feared that if they needed cancer treatment again, their history would prevent them from getting care under the ACA despite several provisions in the ACA that provide protections for individuals with pre-existing conditions.^{6,17} Clear explanations about the consumer protections offered in the ACA and their relevance to cancer survivors could help to ease survivors' stress related to the ACA.

This study has certain limitations. First, these interviews were conducted just before the Supreme Court ruling on the ACA in June 2012. Survivors' opinions or knowledge of the law may have changed as a result of media coverage of the decision; however, as debate about the ACA has been ongoing since it was passed in March 2010, it is unlikely that this recent ruling affected survivors' familiarity substantially. Second, there were few uninsured and racial/ethnic minority participants, limiting our ability to identify themes pertaining to the most underserved survivors. Third, differences in ACA support by political affiliation,²³ which we did not ask about, could have influenced our findings. However, the themes we generated include both positive and negative feelings about the ACA, suggesting the interviewees represent a range of political perspectives. Fourth, our sample was drawn from Utah's cancer registry. Although ACA opinion does differ regionally,²⁴ the themes we elicited will most likely be common for many survivors as a result of the general lack of knowledge about the ACA.^{11,25}

Our findings suggest that both insured and uninsured survivors could benefit from targeted education to assist them with obtaining the best health insurance available under the ACA. Although the ACA provides insurance protections and coverage options that should benefit high-risk cancer survivor populations,¹⁶ the impact of the ACA on uninsured and low-income childhood cancer survivors is not fully known. Communication strategies need to be tested and implemented in vulnerable populations, like childhood cancer survivors, to ensure they benefit from the increased health insurance coverage options that are the hallmark of the ACA.

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References

- Mariotto AB, Rowland JH, Yabroff KR, et al: Long-term survivors of childhood cancers in the United States. *Cancer Epidemiol Biomarkers Prev* 18:1033-1040, 2009
- National Cancer Institute: SEER Cancer Statistics Review 1975-2009. Bethesda, MD, National Cancer Institute, 2009
- Geenen MM, Cardous-Ubbink MC, Kremer LC, et al: Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *JAMA* 297:2705-2715, 2007
- Oeffinger KC, Nathan PC, Kremer LC: Challenges after curative treatment for childhood cancer and long-term follow up of survivors. *Hematol Oncol Clin North Am* 24:129-149, 2010
- Kirchhoff AC, Kuhlthau K, Pajolek H, et al: Employer-sponsored health insurance coverage limitations: Results from the Childhood Cancer Survivor Study. *Support Care Cancer* 21:377-383, 2012
- Moy B, Polite BN, Halpern MT, et al: American Society of Clinical Oncology policy statement: Opportunities in the Patient Protection and Affordable Care Act to reduce cancer care disparities. *J Clin Oncol* 29:3816-3824, 2011
- Wolfson J, Ruccione K, Reaman GH: Health care reform 2010: Expected favorable impact on childhood cancer patients and survivors. *Cancer J* 16:554-562, 2010
- Gruber J, Perry I: Realizing health reform's potential: Will the Affordable Care Act make health insurance more affordable? <http://www.commonwealthfund.org/Publications/Issue-Briefs/2011/Apr/ACA-Health-Insurance-Affordable.aspx>
- Galer-Unti RA: The Patient Protection and Affordable Care Act: Opportunities for prevention and advocacy. *Health Promot Pract* 13:308-312, 2012
- Henry J. Kaiser Family Foundation: Nation still divided on ACA. <http://kff.org/health-reform/slide/nation-still-divided-on-aca/>
- Henry J. Kaiser Family Foundation: Kaiser health tracking poll. <http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-march-2012/>
- Steliarova-Foucher E, Stiller C, Lacour B, et al: International Classification of Childhood Cancer, third edition. *Cancer* 103:1457-1467, 2005
- Krippendorff K: Content Analysis: An Introduction to Its Methodology (ed 3). Thousand Oaks, CA, Sage Publications, 2013

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- Guest G, Bunce A, Johnson L: How many interviews are enough? An experiment with data saturation and variability. *Field Meth* 18:59-82, 2006
- Henry J. Kaiser Family Foundation: Majority say the don't understand how ACA will impact them, including two-thirds of uninsured and low-income. <http://kff.org/health-reform/slide/majority-say-they-dont-understand-how-aca-will-impact-them-including-two-thirds-of-uninsured-and-low-income-2/>
- Villani G: Potential of the Patient Protection and Affordable Care Act to reduce cancer care disparities. *J Oncol Pract* 7:340-341, 2011
- Patient Protection and Affordable Care Act. H.R. 3590, 2010, 1-906
- Herbert G, Hunter E: State of Utah comprehensive health insurance pool: Fiscal year 2011 annual report to the Utah state legislature. <https://insurance.utah.gov/hip/reports.php>
- Hall JP, Moore JM: Realizing health reform's potential: The Affordable Care Act's Pre-existing Condition Insurance Plan: Enrollment, costs, and lessons for reform. <http://www.commonwealthfund.org/Publications/Issue-Briefs/2012/Sep/Preexisting-Condition-Insurance-Plan.aspx>
- Henry J. Kaiser Family Foundation: Current status of state Medicaid expansion decisions as of May 30, 2013. <http://kff.org/health-reform/slide/current-status-of-the-medicaid-expansion-decision/>
- Jost TS, Rosenbaum S: The Supreme Court and the future of Medicaid. *N Engl J Med* 367:983-985, 2012
- Rosenbaum S, Westmoreland TM: The Supreme Court's surprising decision on the Medicaid expansion: How will the federal government and states proceed? *Health Aff (Millwood)* 31:1663-1672, 2012
- Henry J. Kaiser Family Foundation: Partisans keep their divided views on health law. <http://kff.org/health-reform/slide/partisans-keep-their-divided-views-on-health-law/>
- Brodie M, Deane C, Cho S: Regional variations in public opinion on the Affordable Care Act. *J Health Polit Policy Law* 36(6):1097-1103, 2011
- Park ER, Kirchhoff AC, Zallen JP, et al: Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: Implications for the Affordable Care Act. *J Cancer Surviv* 6:251-259, 2012

