What the Affordable Care Act Means for Survivors of Pediatric Cancer

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In the last 50 years, major therapeutic advances in childhood cancer care have transformed pediatric oncology. Although childhood cancer incidence rates have increased significantly from 1975 to 2006,¹ overall survival rates for childhood cancer have improved dramatically from 58% in the 1970s to 83%, based on the most recent data.² The compound impact of increasing incidence and improving survival is that, today, more than 320,000 individuals live as survivors of childhood cancer in the United States.³ Childhood cancer is not the only health challenge that many of these individuals will face in their lifetimes; a survey of the largest cohort of pediatric cancer survivors revealed that two thirds of all survivors will develop a chronic medical condition, with more than one-third experiencing a severe or life-threatening condition.⁴

Nonetheless, the inadequacies of survivorship health care are well recognized. From the paradigmatic longitudinal cohort of childhood cancer survivorship, the Childhood Cancer Survivor Study, it is clear that fewer than half of adult survivors received a cancer-related visit in the last 2 years and that patients without health insurance are most at risk for lack of appropriate follow-up.⁵ Among those who sought clinical follow-up, patients who were black, older at the interview, or uninsured were less likely to receive risk-based, survivor-focused care, and fewer than half received survivor-focused risk-based screening.⁶ Difficulty acquiring health insurance is a common problem for adult survivors of childhood cancer (29% in a separate Childhood Cancer Survivor Study had difficulty with insurance coverage) compared with only 3% in a comparison cohort of the survivors' siblings.⁷

In the context of such challenges in childhood cancer survivorship care, the Patient Protection and Affordable Care Act (ACA) enacted in 2010 offers remarkable opportunities for improvement. As the largest initiative in US health care reform since the enactment of Medicare and Medicaid in 1965, the ACA attempts to eliminate many health care coverage barriers for uninsured individuals in general. Although there are no provisions of the ACA specific to pediatric cancer survivors, those survivors are disproportionately likely to be uninsured or underinsured as adults. Therefore, several provisions of the ACA designed to broaden insurance coverage are relevant for the childhood cancer survivor community. Although they are perhaps unfamiliar to many clinicians in pediatric and adult oncology, specific provisions of the ACA broadly transform patterns of health care for this rapidly growing population. These provisions are summarized in Table 1.

Potential Expansion of Coverage Through the ACA

Five separate provisions of the ACA are expected to help pediatric cancer survivors gain insurance coverage (Table 1).⁸ First, pediatric cancer survivors can no longer be refused coverage or have their coverage cancelled as a result of preexisting medical conditions. Second, young adults may remain on their parents' private health insurance plans up to the age of 26 years. Third, states can choose to raise the minimum eligibility requirements for Medicaid to 133% of the federal poverty level, with this coverage expansion financed in full by the federal government for the first 3 years. In states that decided to

Table 1. Specific Provisions of the ACA With Implications for Insurance Coverage of Adult Survivors of Pediatric Cancer

Provision of the ACA	Implications for Pediatric Cancer Survivors
Prohibition of discrimination on the basis of health status (section 1201)	No denial or cancellation of insurance coverage due to preexisting condition or development of a new condition.
Coverage on parents' insurance (section 1215)	Mandatory coverage allowed up to age 26 years on parents' private insurance plan.
Change in minimum income eligibility for Medicaid (section 2001)	States can decide to raise the Medicaid minimum eligibility to 133% of federal poverty level.
No annual or lifetime coverage limits (section 2711)	Insurance companies can no longer set annual or lifetime coverage limits for medical services.
State-based exchanges (section 1311)	Each state will have a marketplace to purchase health insurance, with subsidies for qualifying individuals.

NOTE. Based on authors' interpretations of specified sections of the ACA.⁸
Abbreviation: ACA, Patient Protection and Affordable Care Act.

expand Medicaid (approximately half are choosing not to do so, a right protected by the supreme court in 2012⁹), this will be the first time that low-income adults without children will be ensured coverage through Medicaid without the need for a federal waiver. Fourth, insurance companies will no longer be able to set annual or lifetime coverage limits for medical services. Fifth, state-based exchanges are to be fully enacted by 2014 with subsidies for premiums and expanded coverage available depending on income and family size to increase affordability of health insurance.

States were given the option to build a fully state-based exchange, enter into a state-federal partnership exchange, or default into a federally facilitated exchange. As of May 28, 2013, 17 states had chosen to run their own exchanges, seven were planning a partnership exchange, and 27 had defaulted to a federal exchange.¹⁰ In an effort to immediately improve insurance coverage, fully federally funded high-risk insurance pools were started in August of 2010 to temporarily cover all patients with medical needs who lacked health insurance for at least 6 months. The pools were to be run by the state or federal government and were intended to bridge coverage until further enactments occurred in 2014. Despite the \$5 billion set aside by the federal government to cover the high-risk pools, there was greater demand than expected for this program, and financial constraints led to suspension of further enrollment in February of 2013.¹¹

According to the ACA, the only essential health benefits that are required to be covered with no out-of-pocket costs by insurance companies are those that meet the qualification of A or B ratings in the current recommendations by the United States Preventive Services Task Force (USPSTF).⁸ Therefore, coverage does not convey full benefits that would be clinically relevant for adult survivors of pediatric cancer. Although the ACA insists on a package of essential health benefits at the core of all health plans, the Children's Oncology Group (COG) recommends screening tests specific to an individual's prior cancer and treatment history that may include diagnostic and imaging evaluations that are not covered in all plans.¹² For example, if a 16-year-old young woman was treated for Hodgkin lymphoma, involving the mediastinal region, for which she received chemotherapy, including anthracyclines and chest radiation of 21 Gy, the COG Long-Term Follow-Up Guidelines would recommend that she receive: echocardiogram every 1 to 2 years after treatment; and beginning at age 25 years, yearly breast mammography and breast magnetic resonance imaging. According to the USPSTF, there are no recommendations for echocardiogram screening, and mammography is not recommended until after the age of 40 years. Therefore, on the basis of USPSTF recommendations alone, childhood cancer survivors will likely face difficulty having screenings related to cancer care follow-up covered without experiencing financial burdens. Clinicians will need to be mindful of potential plan benefit limitations and advocate for their patients to be reimbursed for procedures performed according to COG screening guidelines.

Whether and how expanded coverage for pediatric cancer survivors will translate into better health and health care for them must be examined. In 2008, as a result of programmatic financial constraints, Oregon implemented a lottery system to allow uninsured, low-income adults of all health statuses a chance to apply for Medicaid. Those patients who won the lottery and were enrolled in Medicaid had higher health care use and lower out-of-pocket medical expenditures and medical debt than their peer controls. This group also self-reported better physical and mental health than the control group.¹³

Similarly, currently uninsured survivors of pediatric cancer who gain coverage may demonstrate more appropriate health care use than they have in prior years.

Individual Mandate

Despite the opportunities for new insurance coverage presented by the ACA, it is possible that adult survivors of pediatric cancer may not opt for coverage. In fact, in a recent qualitative study of pediatric cancer survivors, Park et al¹⁴ found that most uninsured survivors minimized their need for health care. Opting out of health insurance—whether resulting from minimizing one's own health care needs or other factors such as affordability—is also addressed by the ACA, through the provision that establishes an individual mandate for insurance coverage.

As one of the most contentious aspects of the ACA, which was declared constitutional by the supreme court in a landmark decision in 2012,⁹ Section 1501 requires individuals to maintain a minimum amount of health care coverage per month or pay a penalty.⁸ The penalty will be implemented as a decrease in the individual deduction on the federal tax return starting in 2015 (applied to 2014 taxes) and is slated to grow from \$95 per person (or 1% of yearly salary, whichever is greater) in 2014 to \$695 per person (or 2.5% of yearly salary) by 2016. Individuals at low incomes may qualify for hardship exemptions from the mandate penalty. This provision may represent a turning point for some pediatric cancer survivors who would otherwise have chosen to go without coverage.

With the expansion in coverage and requirement for enrollment in health insurance, future studies of childhood cancer survivors could help us gain an understanding of the impact of the ACA on this unique patient population. Key features that should be investigated include the ability to obtain or maintain health insurance, measures of underinsurance, and evaluation of access to health care. Underinsurance markers such as out-of-pocket costs and ability to fill prescriptions could be studied. Given that coverage does not always equate with access, changes in the proportion of childhood cancer survivors who have a primary care physician and whether they have been seen in the last 1 to 2 years should be assessed. In addition, it would be worthwhile to investigate childhood cancer survivors' experiences obtaining coverage and reimbursement for COG-recommended screenings based specifically on their cancer and treatment as compared with the ACA-mandated essential health benefits preventive screenings, based on the USPSTF guidelines.

Coverage and Consequences

On the eve of the implementation of the most far-reaching provisions of the ACA, health care for adult survivors of pediatric cancer has much to gain. Physicians can empower themselves with knowledge about implementation of the health insurance exchanges (which opened October 1, 2013) by visiting the Health Insurance Web Portal at healthcare.gov and foundation Web sites such as American Cancer Society and the Kaiser Family Foundation. The American Cancer Society has a free, user-friendly guide designed for patients with cancer that outlines how health care reform will improve their quality of care and make access to health care easier.¹⁵ In addition, foundations such as Livestrong can provide free, confidential insurance navigation services to survivors.¹⁶ By being prepared to answer patients' questions and by encouraging pediatric cancer survivors to engage and stay

connected to the health care system for active follow-up and recommended surveillance,¹² clinicians can help make the ACA a boon for this growing and previously underserved population.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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