The Affordable Care Act and Cancer Care for Young Adults

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Abstract: The Affordable Care Act (ACA) requires health plans that provide coverage for dependents to cover adult children to age 26 years. Extensive evidence has shown that since its implementation in September 2010 insurance coverage and access to care for young adults in the general population have increased. This article reviews the studies that have evaluated the impacts of the ACA on access to cancer care and outcomes for young adults aged 19 to 25 years. Current literature shows that the ACA increased insurance rate and cancer diagnosis at early stage for young adults. There is also evidence of the ACA’s positive effects on initiation and completion of human papillomavirus vaccination and receipt of fertility-sparing treatment for cervical cancer among young women. Several avenues of future research on the ACA and cancer care are suggested.

Key Words: Access to care, Affordable Care Act, cancer screening, cancer stage at diagnosis, cancer treatment, cervical cancer, dependent coverage expansion, HPV vaccination, insurance

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Since September 23, 2010, the Affordable Care Act (ACA) has allowed young adults to be covered under their parents’ health insurance policy until the age of 26 years. This dependent coverage expansion (DCE) has been one of the most popular components of the ACA and will most likely to continue to apply to any reform of the ACA. This article aims to review the impact of the ACA-DCE on access to cancer care and outcomes among young adults. We will first briefly describe the burden of cancer among the young adult population and the health care challenges young adult cancer patients and survivors face. Since the upper age limit of young adulthood in the pre-ACA studies varied from mid-20s to 40s depending on the context of studies, our presentation of the burden and health care challenges is not limited to the targeted population covered by the ACA-DCE. We will then review and summarize the recent evidence on ACA’s impact on various aspects of cancer care and outcomes, focusing on the young adult population of 19 to 25 years old. The ACA also expanded insurance for young adults aged 26 and older through the exchanges and Medicaid, but because those expansions occurred more recently, there are currently limited data about the effects. Lastly, we will suggest avenues for future research to fill the knowledge gaps and inform policy.

CANCER AMONG YOUNG ADULTS

Although cancer occurs less frequently in young adults than among those of older ages in the United States (Fig. 1), it is a leading cause of death in this group. Furthermore, unlike the decreasing trend in older adults, the incidence of cancer has been increasing in young adults since 2000 (Fig. 2). In addition, progress in improvement of cancer survival due to advances in early detection and treatment in young adults has not matched that in children and in older adults. For example, 5-year cancer relative survival between 1975–1977 and 2008–2010 increased from 71% to 84% in young adults 15 to 39 years old, compared with increases from 58% to 83% in children (0–14 years) and from 46% to 64% in those 50 years or older.

According to estimates from the American Cancer Society, approximately 81,750 incident cancer cases were diagnosed at the ages of 15 to 39 years in the United States in 2013, including 13,282 cases among those aged 19 to 25 years, accounting for 0.8% of incident cancer cases of all age groups. The spectrum of cancer in young adults is distinct from that in older populations (Fig. 3). Lymphoma, testicular cancer, thyroid cancer, and melanoma are the most prevalent cancers in young adults. However, leukemia and central nervous system cancers, the most commonly diagnosed cancers in children, also frequently occur in young adults. Breast and cervical cancer, which are more commonly diagnosed at older ages, are also among the most common cancers in young women (Fig. 3).

Young adult cancer patients and survivors have difficulties in employment, educational attainment, and financial stability resulting from their cancer diagnosis. They also face many special challenges related to their health care, such as adherence to therapy, transitions between pediatric and adult oncologists, transitions in medical management between oncologist and primary physician during survivorship, low enrollment in clinical trials, issues in sexuality and fertility, and psychosocial care.

Delays in access to cancer care and diagnosis, which are associated with poor outcomes, are another major challenge for young adult patients. Such delays are largely due to their historically high uninsured rate. Prior to the ACA, young adults had the highest uninsured rate of any age group in the United States (Fig. 4), which can be explained somewhat by their perception of invulnerability and probably more so by the reality of less-stable finances and low access to employer-based insurance.

Compelling evidence from studies among adolescents and young adults with a diagnosis of various types of cancers prior to the ACA has shown that inadequate health insurance is associated with longer time from the onset of first cancer-specific symptom or sign to definitive diagnosis, higher likelihood of advanced stage at presentation, and decreased receipt of definitive treatment. Patients with insurance coverage tended to have a longer survival; in particular, those patients with private insurance were less likely to die of cancer compared with those without a private insurance. Among young adult survivors of childhood cancer, studies have found that uninsured survivors had lower utilization of both cancer-related and general health care, notwithstanding the difficulties obtaining and maintaining health insurance for young adult survivors who recently received a diagnosis of cancer.

In recognition of the challenges young adults faced in meeting their health care needs, the ACA-DCE was intended to bring more affordable health insurance and more accessible health care to young adults 19 to 25 years of age.
THE IMPACTS OF ACA-DCE

Since its implementation in September 2010, several studies conducted in the general population have shown that the ACA-DCE increased insurance coverage among the young adults targeted by the policy. According to estimates from the National Health Interview Survey (NHIS), a household survey of the US civilian noninstitutionalized population administered by the National Center for Health Statistics, the uninsured rate among 19- to 25-year-olds decreased from 33.8% in 2010 to 19.7% in 2014 (Fig. 4). A further examination by family income showed that the drop in late 2010 and early 2011 was associated with the DCE provision in younger adults with higher-income parents, whereas the drop in 2014 was associated with Medicaid expansion for low-income individuals. Data from multiple national surveys also showed that the DCE was associated with improved access to care among young adults 19 to 25 years old, specifically with regard to having a usual source of care and not delaying or forgoing care due to financial reasons. Studies also showed reduction in out-of-pocket costs and improved self-reported health status in young adults 19 to 25 years old following the implementation of the DCE. Evidence regarding the impact of the DCE on care utilization is less consistent, with some studies finding increased preventive services use, reduced emergency department visits, or increased hospital inpatient use, whereas others found no effect.

Compared with the evidence among the general population, data on the impact of the ACA-DCE on access to and utilization

P-values: <0.01 <0.01 <0.01 <0.01 <0.01 NS NS <0.01 <0.01 <0.01 <0.01 <0.01 <0.01 <0.01

FIGURE 1. Incidence rate of malignant cancer in 2013. Data from surveillance, epidemiology, and end results program 18 registries.

FIGURE 2. The annual percent change in the incidence of malignant cancer by age group from 2000 through 2013. Data from surveillance, epidemiology, and end results 18 registries. NS, nonsignificant. Adapted from Barr et al.
of care and health outcomes among cancer patients or survivors are relatively sparse. In the following sections, we summarize the available data on insurance coverage among young cancer patients, vaccination against human papillomavirus (HPV) infections and cervical cancer screening among young women, stage at diagnosis, and receipt of treatment among young cervical cancer patients.

Insurance Coverage

Using data from Surveillance, Epidemiology, and End Results (SEER) 18 registries, population-based cancer registries covering 28% of the US population, Parson et al.40 examined insurance rates before (January 2007 to September 2010) versus after (October 2010 to December 2012) ACA-DCE among 39,632 young adults aged 18 to 29 years diagnosed with first malignant primary incident cancer. The authors conducted a difference-in-differences (DD) analysis, in which the intervention group, patients aged 18 to 25 years, were compared with the control group, patients aged 26 to 29 years, using multivariate logit models. They found a 3.1 percentage-point ($P < 0.01$) increase in overall insurance rates in those aged 18 to 25 years compared with individuals aged 26 to 29 years, but no change in Medicaid enrollment, thereby demonstrating a positive impact of the DCE on insurance rates in the young adult cancer patients.

Another study using the same data set (SEER-18 registries 2007–2012) but with a slightly different study design—where year 2010 was excluded as a washout/phase-in period and linear probabilities models were fitted for DD analysis—found a decrease of 2.0 percentage points (95% confidence interval [CI], 0.7–3.4 percentage points; $P = 0.004$) in uninsured rate for patients aged 19 to 25 years compared with patients aged 26 to 34 years.41

HPV Vaccination

On the same day as the DCE implementation, another provision of ACA eliminated cost sharing for targeted preventive services, including HPV vaccines, which prevent cervical cancer, for females up to age 26 years. This vaccine may also prevent other cancers, such as cancers of the vagina and vulva in women, cancers of the penis in men, and cancers of the anus and oropharynx in both women and men.42

A study with 10,010 women aged 18 to 26 years identified from the 2008–2012 NHIS analyzed the change in reporting ever initiating (having ≥1 vaccine doses) and completing (having 3 vaccine doses) the HPV vaccine, awareness of HPV, and awareness of the HPV vaccine before and after October 1, 2010. Difference-in-differences analysis was conducted using linear regression models.43 The study found that the likelihood of HPV vaccine initiation and completion increased by 7.7 ($P < 0.01$) and 5.8 ($P < 0.05$) percentage points, respectively, for women aged 19 to 25 years relative to the control group of women aged 18 or 26 years, translating to 1.1 million young women initiating and 854,000 young women completing the HPV vaccine series because of the ACA. The study did not find significant changes in awareness of HPV or HPV vaccine, suggesting that the contribution of awareness to the increase in HPV vaccine initiation and completion was limited.
Papanicolaou Test

The Papanicolaou (Pap) test identifies precancerous cervical lesions and early cervical cancer cells. The American Cancer Society, US Preventive Services Task Force, and the American College of Obstetricians and Gynecologists all recommend a regular Pap test for all women without total hysterectomy between ages of 21 and 65 years.44

In a study with data from the nationally representative Medical Expenditure Panel Survey, we examined the changes in self-reported receipt of Pap test within the year before (2009) and after (2011–2012) the ACA-DCE among women 21 to 25 years old, using women 26 to 30 years old as a control group.41 We found that the receipt of Pap test changed little over this period in both age groups. While this finding did not support a positive effect of the ACA, we suspect that the pattern may reflect changes made around that time in recommendation of Pap test from annually to every 3 years with an added option of cotesting with HPV testing every 5 years for women aged 30 to 65 years.45–47

Stage at Diagnosis

From the National Cancer Data Base (NCDB), a national hospital-based cancer registry that captures approximately 70% of all malignant cancers in the United States each year, our group identified 3927 cervical cancer patients aged 21 to 34 years diagnosed in 2007–2009 (pre-ACA) and 2480 cases diagnosed in 2011–2012 (post-ACA).48 Using a DD approach and fitting linear probability models, we found that compared with 26- to 34-year-old women, those aged 21 to 25 years experienced a net increase of 9.0 percentage points (95% CI, 2.0–16.2 percentage points) in early stage (I/II) disease (P = 0.01). After adjustment for multiple sociodemographic factors, the net increase remained statistically significant (7.6 percentage points; 95% CI, 0.3–14.8 percentage points; P = 0.04).

In an article published in 2016, we extended the NCDB study to examine changes in stage at diagnosis for all cancers among young adults using data from SEER-18 registries that included 44,669 patients diagnosed with first primary cancer.43 This analysis utilized a quasi-experimental study design in which cancer patients aged 19 to 25 years were in the intervention group and those aged 26 to 34 years were in the control group; a diagnosis year of 2007–2009 was considered pre-ACA period and 2011–2012 was post-ACA period. Difference-in-differences analysis was conducted using linear probability models. The study observed an increase of 2.7 percentage points (95% CI, 0.6–4.8 percentage points) in diagnosis at stage I for patients aged 19 to 25 years relative to the patients aged 26 to 34 years, after adjustment for available sociodemographic factors. Further analyses by specific cancer site revealed statistically significant shifts for carcinoma of the cervix (21.2 percentage points; 95% CI, 9.6–32.7 percentage points), confirming the finding from the NCDB study48; a statistically significant increase in stage I disease was also observed for osseous and chondromatous neoplasms (14.4 percentage points; 95% CI, 0.3–28.5 percentage points), which mostly occur in the oral cavity and are amenable to early detection during a dental examination. As we discussed in that article, this coincided with increases in dental insurance coverage and dental checkups as spillover effects of the ACA-DCE.41 Although not statistically significant, this shift to early-stage disease was also seen in half of the 14 remaining cancers in the study that were prevalent in young adults. The patterns of stage at diagnosis for these cancers merit future monitoring.

Treatment

In the cervical cancer study using NCDB,48 we also examined the changes in use of fertility-sparing treatments. We found that between the pre- (2007–2009) and post- (2011–2012) ACA-DCE periods, compared with 26- to 34-year-old cervical cancer patients, those aged 21 to 25 years experienced a net increase of 11.9 (95% CI, 4.3–19.5) percentage points in receipt of fertility-sparing treatments (P = 0.002), and 13.4 (95% CI, 5.8–21.0) percentage points after adjustment for sociodemographic factors (P = 0.001).

Summary

The ACA-DCE has substantially increased insurance coverage for young adult cancer patients aged 19 to 25 years old. The current literature also shows evidence of positive effect of the ACA-DCE for young women on initiation and completion of HPV vaccination and early diagnosis and receipt of fertility-sparing treatments for cervical cancer. Studies also show increases in early-stage diagnosis for total cancer and osseous and chondromatous neoplasms among young adults 19 to 25 years old after the implementation of the DCE. The study examining uptake of the Pap test did not observe a change.

FUTURE RESEARCH DIRECTIONS

Given the high popularity of the ACA-DCE among both consumers and the current administration, any new policy by the current administration to replace or revise the ACA will likely keep the DCE provision. Future research is warranted to monitor the effects of this provision on many aspects of cancer care for young adults, such as enrollment in clinical trials and psychosocial supportive care, receipt and delay in treatment, and the financial burden of cancer care. Its effect on the health outcomes of young adult cancer patients and survivors, such as survival and quality of life, should be monitored as well when data become available.

The DCE is not the only component of the ACA that can affect cancer care among young adults. As shown in a previous study, the Medicaid expansion has also substantially decreased the uninsured rate in the states that opted in, especially for the young adults with low family income.27 How the Medicaid expansion affects cancer care among young adults needs to be examined, as well as the establishment of the marketplace exchange that makes private insurance more affordable and accessible to low- and middle-income young adults (and families) with subsidies and prohibitions of preexisting condition exclusions and lifetime and annual coverage limits. These prohibitions are important for cancer patients and survivors. The elimination of cost sharing for recommended preventive services, including smoking cessation and obesity screening and counseling, can also reduce cancer risk and positively impact quality of life in young adults. Timely evidence of these ACA components’ effect on cancer care and outcomes among young adult population will further inform policy for the ongoing health reform.

REFERENCES

2. What should the age range be for A Y A oncology? J Adolesc Young Adult Oncol. 2011;1:3–10.
Adolescent and Young Adult Oncology Progress Review Group. Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer—Report of the Adolescent and Young Adult Oncology Progress Review Group. National Cancer Institute; Bethesda, MD: National Cancer Institute; 2006.


National Center for Health Statistics. Health, United States, 2008 With Special Feature on the Health of Young Adults. Hyattsville, MD: Sub; 2009.


