Insurance Coverage, and Having a Regular Provider, and Utilization of Cancer Follow-up and Noncancer Health Care Among Childhood Cancer Survivors

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Abstract
The objective of this study was to assess the role of health insurance coverage on patterns of health care utilization and access to cancer-related follow-up and non-cancer care among childhood cancer survivors (CCS). Cross-sectional survey design was used. Childhood cancer survivors were from 2 large hospitals in Los Angeles County. In all, 235 were identified through the Los Angeles Cancer Surveillance Program, diagnosed between the ages of 5 and 18 in 2000-2007 with any cancer type except Hodgkin lymphoma. At data collection in 2009-2010, participants were between 15 and 25 years old. Study exposure was health insurance coverage (private, public, and uninsured). Main outcomes and measures were respondents’ regular source of care for cancer follow-up, noncancer care, and both; and having a cancer follow-up visit, primary care visit, and hospital emergency department visit in the past 2 years. Compared with those with private insurance, the uninsured were less likely to have a regular source for cancer follow-up (odds ratio [OR] = 4.3, 95% confidence interval [CI] = 1.9-9.4), less likely to have a source for noncancer care (OR = 3.3, 95% CI 1.6-6.9), and less likely to have a source of care for both (OR = 5.3, 95% CI = 2.1-13.5). Furthermore, uninsured CCS were less likely to have made visits to cancer specialists (OR = 4.5, 95% CI = 2.1-9.50) and were less likely to have seen a primary care physician in the past 2 years (OR = 3.9, 95% CI = 1.8-8.2). In addition, those with public (vs private) insurance were less likely to have a regular provider for primary care (OR = 2.5, 95% CI = 1.1-5.4) and less likely to have made a primary care visit in the past year (OR = 2.8, 95% CI = 2.1-13.5). Uninsured CCS are at risk of not obtaining cancer follow-up care, and those with public (vs. private) insurance have less access to primary care. Policies that ensure continuity of coverage for survivors as they age into adulthood may result in fewer barriers to needed care, which may lead to fewer health problems for CCS in the future.

Keywords
childhood cancer survivors, access barriers, health insurance, regular source of care

Introduction
Policy-driven changes in the financing and delivery of health care services have dramatically increased the number of people with health insurance and access to care.¹ To identify disparities and to monitor the impact on health resulting from changes in public policies, many health services studies have focused on large populations seeking to understand patterns of use by socioeconomic, racial and ethnic, or geographic characteristics. However, less is known about how these changes have affected patient groups with special needs, especially among minority populations. Studies of smaller populations defined by disease state can be an important contribution to understanding how access barriers interact with the changing health care system, for those who face barriers in obtaining needed care, particularly Latinos.

One group with unique needs is childhood cancer survivors (CCS). The survival rate for childhood cancer has improved greatly in recent decades.²,³ Still, childhood and adolescent CCS face many challenges as they transition from the pediatric to the adult health care system, including losing health coverage. Childhood cancer survivors are at increased

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Received 27 November 2017; revised 8 November 2018; revised manuscript accepted 16 November 2018

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risk of chronic health conditions and other adverse effects of their treatments, including second cancers and early-onset heart disease. As a result, CCS are recommended to participate in annual survivor-focused medical surveillance. Staying connected to the health care system is important for CCS because many are at risk of long-term health issues, known as late effects, due to the treatments received for their cancer. Childhood cancer survivors also have general health needs, including episodic care for acute illnesses, management of other chronic problems, preventive services, and mental health care.

Although many require lifelong surveillance to monitor cancer-related morbidities, as CCS get older, their continuity of care is often compromised during the transition to adult care. The proportion of young adult survivors who return for follow-up care rapidly declines with age and time off treatment, resulting in inadequate surveillance for late effects and missed opportunities for psychosocial support and health promotion.

Overcoming financial and non-financial barriers to care is important for CCS who need both cancer-related and primary care. For example, health insurance reduces the financial barriers to care and helps to establish and maintain clinical relationships with providers. In addition, the uninsured and those with public coverage are more likely to use the hospital emergency department (ED). Lack of health insurance and type of coverage are also strong predictors of use of cancer follow-up care by CCS. Other barriers to receiving services include scheduling conflicts with work or school, transportation problems, cultural and language issues, and lack of knowledge about how to use available resources.

While the effects of insurance coverage have been previously reported for CCS, less is known about access barriers within the health care system for both cancer and non-cancer-related health services, especially among minority populations. One underreported area is having a regular source of care (RSC). Having a strong connection to a health care provider who can be a regular provider for both cancer follow-up and noncancer care is a determinant to obtaining a broad range of timely health and mental health care services. If a person does not have a specific provider that he or she relies on for care, that individual is less likely to obtain needed health services.

Utilization of cancer follow-up reflects the ability of CCS to access specialized oncology care, while use of primary care likely reflects use of services in response to general health care services that are not related to cancer care. ED use in some instances has been shown to reflect a barrier to receiving primary care in a more appropriate ambulatory care setting, and we have used that as one proxy measure of a barrier to primary care.

In this article, we analyze data from a cohort of young adult survivors of pediatric cancer diagnosed between the years 2000-2007. We examine health insurance coverage, having regular sources of cancer-related follow-up care and primary care, and health care utilization patterns for cancer-related, noncancer, and emergency care among ethnically diverse CCS. We analyze how CCS experience both cancer follow-up and non-cancer care, and we hypothesize that CCS may have more difficulties in obtaining non-cancer care as they get older and transition to the adult-oriented system. While a limited number of other studies have examined the impact of insurance coverage on health utilization in this population, the present study is unique due to the high proportion (56%) of Hispanic/Latino survivors represented and the assessment of both regular (non-cancer) care and acute care. Moreover, the data were collected from a period before the implementation of the Patient Protection and Affordable Care Act (ACA) which likely had an impact on access to care for this population. However, this period reflects what might be a likely effect on access if many provisions of the ACA are repealed, particularly the elimination of the current regulations that restrict discrimination against people with preexisting health conditions.

Methods

The data used in this study are from the Project Forward pilot study. A survey in English and Spanish was mailed to a cohort of CCS diagnosed with any type of cancer (except Hodgkin lymphoma) between 2000 and 2007 from 2 large pediatric medical centers in Los Angeles County. Patients with Hodgkin lymphoma were excluded because they were included in another registry study, and cancer registry policies prohibit enrollment of cases in more than one study per year to reduce participant burden. Participants were diagnosed between the ages of 5 and 18 years and were aged between 15 and 25 years at the time of data collection beginning in 2009. Childhood cancer survivors were identified through the Los Angeles Cancer Surveillance Program, the Surveillance, Epidemiology, and End Results (SEER) Cancer Registry covering Los Angeles County. Each patient was mailed a survey to complete in 2010, and recruitment occurred over a 12-month period. More details about the study procedures have been described elsewhere. After extensive follow-up efforts, the recruitment rate for the study was 50%, comparable to or exceeding similar studies. No differences were found between respondents and non-respondents in comparisons of registry data for age, race/ethnicity, or clinical variables. Only gender and socioeconomic status (SES) of census tract of residence were found to be significantly different, with women more likely to respond to the survey than men and those from higher income areas more likely to respond than those from lower income areas. However, no differences in response by SES were seen between respondents and non-respondents. The data used in this study are from the Project Forward pilot study. A survey in English and Spanish was mailed to a cohort of CCS diagnosed with any type of cancer (except Hodgkin lymphoma) between 2000 and 2007 from 2 large pediatric medical centers in Los Angeles County. Patients with Hodgkin lymphoma were excluded because they were included in another registry study, and cancer registry policies prohibit enrollment of cases in more than one study per year to reduce participant burden. Participants were diagnosed between the ages of 5 and 18 years and were aged between 15 and 25 years at the time of data collection beginning in 2009. Childhood cancer survivors were identified through the Los Angeles Cancer Surveillance Program, the Surveillance, Epidemiology, and End Results (SEER) Cancer Registry covering Los Angeles County. Each patient was mailed a survey to complete in 2010, and recruitment occurred over a 12-month period. More details about the study procedures have been described elsewhere. After extensive follow-up efforts, the recruitment rate for the study was 50%, comparable to or exceeding similar studies. No differences were found between respondents and non-respondents in comparisons of registry data for age, race/ethnicity, or clinical variables. Only gender and socioeconomic status (SES) of census tract of residence were found to be significantly different, with women more likely to respond to the survey than men and those from higher income areas more likely to respond than those from lower income areas. However, no differences in response by SES were seen between respondents and non-respondents.
Variables
We analyzed survivors’ access to care using the following self-reported outcome measures.

Regular Sources of Care
Three variables were created that measured the types and combinations of RSCs reported by each respondent. Childhood cancer survivors reported separately whether they had an RSC for (1) cancer follow-up care and (2) noncancer-related care. For both variables, responses were dichotomized as (1) for no RSC and (0) for having an RSC. In addition, a third variable was created to measure having no RSC for both types of care. Respondents who had no RSC for both cancer and noncancer care were scored (1), while all others were scored (0).

Health Care Utilization
Respondents’ use of services in the past 2 years was categorized by the following 3 variables: (1) use of a primary care physician, (2) use of a cancer specialist, and (3) use of a hospital ED. For primary care, respondents were scored (1) if they had no primary care visit in the past 2 years or (0) if they had at least one primary care visit in the past 2 years. For cancer specialist visits, respondents were scored (1) if they had no cancer-related visit in the past 2 years or (0) if they had at least 1 cancer follow-up visit in the past 2 years. For ED visits, respondents were scored (1) if they had at least 1 ED visit in the past 2 years or (0) if they had never visited an ED in the past 2 years.

Health insurance coverage was included as an independent variable and was categorized as public, which includes Medicaid, Medicare, or county-sponsored insurance programs; private, which includes job-based and privately purchased plans; or uninsured/unknown, which includes those reporting that they had no coverage or did not know whether they had coverage.

Covariates included age, dichotomized as under age 21 or age 21 to 25 years (as this age distinction represents the transition from the pediatric to adult care setting), gender, and ethnicity coded as “Hispanic/Latino” or “other.” The SES was estimated using an established area-based composite of multiple socioeconomic indicators from census sources, as previously published.\(^\text{21,22}\) The SES measure was developed by the CCR for all census block groups in the state (5 quintile groups: 1 = lowest SES, 5 = highest SES). The SES was coded as low (representing the bottom 2 quintiles) and middle/high, representing the top 3 quintiles.\(^\text{21-23}\) This variable was used because few parents responded directly to the income question from which we could otherwise assess SES. So a parental SES metric on everyone was not available. The SES variable based on census data is used when self-reported income is not available to compare respondents with nonrespondents. It also provides a neighborhood measure that could add additional insights into access to care. We controlled for Latino versus other (non-Latino), but there was insufficient variation in the sample to control for other race/ethnicity categories. Treatment intensity (TI) was based on registry data and medical chart abstraction and categorized by 4 levels: 1 = least intensive (eg, surgery only), 2 = moderately intensive (eg, chemotherapy or radiation), 3 = very intensive (eg, 2 or more treatment modalities), and 4 = most intensive (eg, regimens for relapsed disease including hematopoietic cell transplantation). Treatment intensity was chosen over self-reported health status as it is a validated instrument to measure the extent of cancer treatment among CCS and is a risk factor for late effects.\(^\text{24}\)

Analyses
Bivariate and multivariable analyses were conducted to compare the associations between insurance coverage and 2 overall outcome variables: RSC and health care utilization. The RSC variable is broken into 3 subcategories: 1 = having no RSC for cancer follow-up services, 2 = general primary care, and 3 = both. We also compared the associations between insurance coverage and health care utilization. The dependent variables were 1 = having no cancer follow-up visit and 2 = having no primary care within the past 2 years. A third variable was created, defined as having made at least one ED visit in the past 2 years.

Bivariate (unadjusted) analyses were performed to assess factors associated with each health care utilization outcome variable. Multivariable logistic regression models were developed to assess the independent relationship between health insurance status and each outcome to calculate adjusted odds ratios and 95% confidence intervals (CIs). The model was adjusted for age, ethnicity, gender, SES, and TI. We also analyzed the effect of the interactions between insurance coverage and the other independent variables and covariates, including age, ethnicity, SES, and TI, on the outcome variables. A missing value for covariates and outcome variables were included where appropriate, and cases with missing values were excluded from the analysis.

Although non-significant in the bivariate models, current age, gender, and SES were included in the multivariable models, as these covariates are of theoretical importance in explaining the outcome variables. The level of significance was set to \(\alpha\) less than .05, and tests were 2-sided. All analyses were conducted using SAS statistical software (version 9.4) (SAS Institute, Cary, North Carolina).

Study Results
The majority of CCS were less than 21 years of age (60%), Latino (56%), and female (51%). Just under half (48%) were in the low and mid-low SES categories. Of the sample, 30% were uninsured, with the insured split between public (32%)
and private (38%) coverage. A third (32%) had no regular provider for their cancer care compared with 37% who reported no RSC for non-cancer problems. However, 20% reported no regular provider for either cancer care or general care. Just over one-third had no primary care visit compared with 38% with no cancer specialist visit in the past 2 years; 15% made an ED visit in the past 2 years.

Table 1 shows that almost one-quarter of younger CCS were uninsured compared with 40% of those aged 21 and above. Latinos and those with low SES were all statistically more likely to be uninsured compared with other ethnicities and those with higher SES. There was no statistically significant difference by gender. Younger CCS were more likely to be covered by public programs, as were Latinos and those of low SES. Analysis by TI shows that those with the lowest and the highest TI values were more likely to be uninsured or have public coverage compared with those with more intermediate levels of intensity.

We show bivariate statistics in Table 2, including having no RSC and service utilization. Older CCS were twice as likely to lack an RSC for cancer care (47% vs 22%, $P < .0001$) and noncancer care (53% vs 26%, $P < .0001$) compared with younger CCS (Table 3). Older CCS were 3 times as likely to lack an RSC for either cancer or noncancer care compared with those under 21 (35% vs 9%, $P < .0001$). Latinos were twice as likely to lack an RSC for cancer-related care ($P < .0008$) compared with non-Latinos, but there were no significant differences in having no RSC by ethnicity for noncancer care or for those lacking an RSC for both. No differences were observed in lacking an RSC by gender or SES. The uninsured were more than 2 times as likely to report no RSC for cancer follow-up compared with those with private coverage ($P < .05$). Childhood cancer survivors with public coverage were slightly more likely to report no RSC for general care compared with those with private coverage. Only non-use of cancer specialists by TI was significant ($P < .05$).

We observed differences between all subgroups in 2-year utilization of primary care but fewer in use of cancer-related care or in ED visits. Older CCS were more likely to have made no primary care visit in the past 2 years compared with younger CCS (44% vs 32%, $P < .05$). Latinos were more likely to lack a primary care visit than other ethnicities (44% vs 28%, $P < .05$). Men (44% vs 30%, $P < .05$) and CCS with low SES (43% vs 32%, $P < .05$) were more likely to have no primary care visit in the past 2 years compared with women and those in the higher SES groups. Those without insurance coverage and those with public insurance were more likely to report no primary care visit in the past 2 years compared with those with private insurance (52% and 43% vs 20%, $P < .05$).

For some variables, disparities in the use of cancer follow-up care were also seen. Older CCS were more likely than younger survivors to report no cancer-related visit (46% vs 33%, $P < .0001$), and the uninsured were also more likely to have received no cancer care compared with those with coverage (60% vs 29%, $P < .0001$). No significant differences were observed in cancer follow-up care by ethnicity, gender, and SES. The uninsured were less likely to make a hospital ED

### Table 1. Percent Insured and Uninsured by Age, Ethnicity, Socioeconomic Status, Treatment Intensity, and Gender (N = 235, 234 Excluding Cases With Missing Values), N (%).

|                           | Total N = 235, 234 | No insurance 90 (38.3) | Private/other 75 (31.9) | Public 70 (29.8) |
|---------------------------|-------------------|------------------------|------------------------|-----------------|
| Age                       |                   |                        |                        |                 |
| <21                       | 141 (60.0)        | 32 (22.7)              | 51 (36.2)              | 58 (41.1)       |
| 21-25                     | 94 (40.0)         | 38 (40.4)              | 39 (41.5)              | 17 (18.1)       |
| Ethnicity                 |                   |                        |                        |                 |
| Other                     | 104 (44.3)        | 28 (26.9)              | 57 (54.8)              | 19 (18.3)       |
| Latino                    | 131 (55.7)        | 42 (32.1)              | 33 (25.2)              | 56 (42.8)       |
| Gender                    |                   |                        |                        |                 |
| Female                    | 119 (50.6)        | 42 (35.3)              | 44 (37.0)              | 33 (27.7)       |
| Male                      | 116 (49.4)        | 28 (24.1)              | 46 (39.7)              | 42 (36.2)       |
| Socioeconomic status      |                   |                        |                        |                 |
| High/Middle               | 120 (51.1)        | 31 (25.8)              | 67 (55.8)              | 22 (18.4)       |
| Low                       | 115 (48.9)        | 39 (33.9)              | 23 (20.0)              | 53 (46.1)       |
| Treatment intensity       |                   |                        |                        |                 |
| 1                         | 22 (9.4)          | 8 (36.4)               | 8 (36.4)               | 6 (27.2)        |
| 2                         | 77 (32.9)         | 25 (32.5)              | 33 (43.2)              | 19 (24.7)       |
| 3                         | 105 (44.9)        | 27 (25.7)              | 42 (40.0)              | 36 (34.3)       |
| 4                         | 30 (12.8)         | 9 (30.0)               | 7 (23.3)               | 14 (46.7)       |

*Groups are statistically significantly different, $\chi^2 P < .05$. 
visit in the past 2 years compared with those with public coverage and the privately insured (7% vs 18%, \( P < .05 \)). Those with lower TI were more likely to have no visit to a cancer specialists compared with those with higher TI levels (\( P < .05 \)). All other differences were not significant.

**Table 2.** Regular Source of Care and Use of Services, by Age, Ethnicity, Gender, SES, Insurance Status, and Treatment Intensity, N (%).

| Age      | No RSC cancer care n = 74 (35.7) | No RSC noncancer care n = 87 (42.0) | No RSC both n = 46 (22.2) | No primary care visit n = 88 (40.9) | No visit to cancer specialist n = 92 (42.8) | Made emergency department visit n = 35 (16.3) |
|----------|----------------------------------|-------------------------------------|---------------------------|-----------------------------------|------------------------------------------|---------------------------------------------|
| <21      | 30 (22)*                          | 37 (26)*                            | 13 (9)*                   | 44 (32)*                          | 46 (33)*                                 | 22 (16)                                    |
| 21-25    | 44 (47)*                          | 50 (53)*                            | 33 (35)*                  | 41 (44)*                          | 43 (46)*                                 | 13 (14)                                    |
| Ethnicity | Latino                           | Other                               |                            |                                   |                                          |                                             |
| Latino   | 53 (41)*                          | 52 (40)                             | 31 (24)                   | 56 (43)*                          | 55 (43)                                 | 20 (16)                                    |
| Other    | 21 (20)*                          | 35 (34)                             | 15 (14)                   | 29 (28)*                          | 34 (33)                                 | 15 (15)                                    |
| Gender   | Female                           | Male                                |                            |                                   |                                          |                                             |
| Female   | 38 (33)                           | 40 (34)                             | 23 (20)                   | 35 (30)*                          | 45 (39)                                 | 18 (15)                                    |
| Male     | 36 (31)                           | 47 (41)                             | 23 (20)                   | 50 (44)*                          | 44 (38)                                 | 17 (15)                                    |
| SES      | High/Middle                      | Low                                 |                            |                                   |                                          |                                             |
| High/Middle | 36 (30)                        | 44 (37)                             | 25 (21)                   | 35 (29)*                          | 45 (38)                                 | 22 (19)                                    |
| Low      | 38 (34)                           | 43 (38)                             | 21 (18)                   | 50 (44)*                          | 44 (39)                                 | 13 (12)                                    |
| Insurance status | Private/Other (Ref.) | Public insurance | Uninsured/Unknown | 1.0                               | 0.9 (0.4-2.3)                           | 4.3 (1.9-9.4)                             |
| Private/Other | 20 (23)*                          | 23 (26)                             | 11 (12)*                  | 18 (20)*                          | 26 (29)*                                 | 18 (20)                                    |
| Public   | 16 (21)*                          | 28 (37)*                            | 8 (11)*                   | 32 (43)*                          | 22 (30)*                                 | 12 (16)                                    |
| Uninsured or unknown | 38 (56)*                          | 36 (52)*                            | 27 (39)*                  | 35 (52)*                          | 41 (60)*                                 | 5 (7)*                                     |
| Treatment intensity | 1                               | 2                                  | 3                         | 4                                  |                                           |                                             |
| 1        | 8 (38)                            | 10 (46)                             | 6 (27)                    | 6 (27)                            | 13 (59)*                                 | 4 (18)                                     |
| 2        | 23 (30)                           | 27 (36)                             | 16 (21)                   | 23 (31)                           | 38 (51)*                                 | 13 (17)                                    |
| 3        | 34 (33)                           | 33 (31)                             | 17 (16)                   | 41 (39)                           | 30 (29)*                                 | 13 (13)                                    |
| 4        | 8 (27)                            | 16 (53)                             | 6 (20)                    | 14 (47)                           | 8 (27)*                                  | 5 (17%)                                    |

Note. SES = socioeconomic status; RSC = regular source of care.

*Statistical significance \( P \leq .05 \).

**Table 3.** Insurance Status and Regular Source of Care and Health Care Utilization Outcomes, Adjusted for Age, Gender, Ethnicity (Latino), Socioeconomic Status, and Treatment Intensity.

| Health outcomes | Insurance status | Adjusted odds ratio (95% confidence interval) |
|-----------------|------------------|-----------------------------------------------|
| No regular provider for cancer care | Private/Other (Ref.) | 1.00                                           |
|                  | Public insurance | 0.9 (0.4-2.3)                                  |
|                  | Uninsured/Unknown | 4.3 (1.9-9.4)                                  |
| No regular provider for noncancer care | Private/Other (Ref.) | 1.00                                           |
|                  | Public insurance | 2.5 (1.1-5.4)                                  |
|                  | Uninsured/Unknown | 3.3 (1.6-6.9)                                  |
| No regular provider for cancer or noncancer care | Private/Other (Ref.) | 1.0                                           |
|                  | Public insurance | 1.3 (0.4-3.8)                                  |
|                  | Uninsured/Unknown | 5.3 (2.1-13.5)                                 |
| No primary care visit in the past 2 years | Private/Other (Ref.) | 1.00                                           |
|                  | Public insurance | 2.8 (1.3-6.2)                                  |
|                  | Uninsured/Unknown | 3.9 (1.3-6.2)                                  |
| No cancer specialist visit in the past 2 years | Private/Other (Ref.) | 1.0                                           |
|                  | Public insurance | 1.3 (0.6-2.9)                                  |
|                  | Uninsured/Unknown | 4.5 (2.1-9.5)                                  |
| At least one emergency department visit in the past 2 year | Private/Other (Ref.) | 1.0                                           |
|                  | Public insurance | 0.9 (0.4-2.2)                                  |
|                  | Uninsured/Unknown | 0.4 (0.1-1.1)                                  |
**Multivariable Models**

Multivariable models were produced for all outcomes adjusting for gender, ethnicity (Latino vs non-Latino), age, (under 21 vs 21 years and older), SES, and TI (Table 3). In these controlled models, the uninsured were 4.3 times as likely to have no regular provider for cancer (95% CI = 1.9-9.4), 3.3 times as likely to lack a regular provider for non-cancer care (95% CI = 1.6-6.9), and 5.3 times as likely to lack both sources of care compared with those with private insurance (95% CI = 2.1-13.5). Those with public insurance did not differ from those with private insurance for having a regular source of cancer care, but were 2.5 times as likely to report no regular source of primary care (95% CI = 1.1-5.4).

Similarly, those without insurance were 3.9 times as likely to have had no primary care visit (95% CI = 1.8-8.2) and 4.5 times as likely to have not seen a cancer specialist compared with those with private coverage (95% CI = 2.1-9.5). In addition, those with public insurance were 2.8 times as likely not to have made a primary care visit in the past 2 years compared with those with private coverage, but did not differ from the privately insured in the use of cancer care (95% CI = 1.3-6.2). No statistically significant differences were found in use of ED visits by insurance coverage. In assessing the interactions, we found no significant interaction effect between insurance coverage and age, ethnicity, and TI with any of the outcome variables.

**Discussion**

Our study confirms previous work showing that insurance coverage plays an important role in improving access to both cancer and non-cancer care for CCS. Overall, the uninsured CCS were less likely to have a regular provider for cancer and general (non-cancer) care or both, compared with those with any coverage. Access to cancer specialists was greater for those with both public and private coverage compared with those without insurance, suggesting that either helps to keep people connected to cancer follow-up providers, and both groups seem as likely to have a regular provider for cancer care and make a cancer follow-up care visit. However, the type of coverage is also important. Access patterns were different for general primary care; those with private insurance were more likely to have a regular source of primary care or to have made a primary care visit in the past 2 years compared with those with either public or no insurance. These results suggest that, despite coverage, CCS on Medicaid or other public insurance continue to have a difficult time obtaining primary care compared with those with private plans.

It is noteworthy that there are a high number of Latinos in this sample (over 50%) and that Latinos have a higher likelihood of having no regular provider and a lower likelihood of using services. Differences were especially acute among those aged 21 to 25, an age at which CCS have typically transitioned from pediatric to adult care. These differences persisted even after controlling for insurance status. Additional research and/or services focused on transitional care are warranted. These overall findings are consistent with other studies showing the disparity in access to care for the Latino population and their slow enrollment in both public (Medicaid) and private coverage after the passage of the ACA.

While the uninsured CCS and those on Medicaid may be able to obtain primary care through safety net providers such as public hospitals and/or federally qualified health centers, these providers are often overcrowded with demand typically beyond their capacity in many communities. Finally, it is noteworthy that 1 in 5 CCS lack access to a regular provider for both forms of care, suggesting that the health care system is largely out of reach for many survivors as they get older and transition from pediatric to adult care.

One of the limitations of the study is that we could not examine the reasons for visiting a specific type of provider. Depending on the scope and severity of their cancer diagnosis and treatment, CCS could get cancer-related follow-up care from a variety of clinicians, including primary care physicians, as well as cancer specialists. Those who rely on primary care physicians, or even hospital EDs for cancer-related care, may not be receiving appropriate long-term cancer follow-up care. Even if it is a goal to transfer cancer care to the primary care provider, some primary care clinicians may not have the skills or expertise to properly manage cancer follow-up care. Although oncologists may also be able to respond to at least some primary care problems, these clinicians may have less time or comfort level to appropriately respond to the more general health problems presented by CCS. The ED use reflects response to emergent problems, but people also use the ED for non-emergency care when they face obstacles in gaining access to cancer follow-up care or general health care services. This study could not differentiate true emergency care from those seeking ED services due to an access problem for nonurgent conditions.

**Conclusions and Policy Implications**

These data show the important role that health insurance plays in promoting a continuum of care for cancer survivors as they transition to adulthood and adult health care settings. It also shows that the disparities that persist in access to care for Latino cancer survivors in the United States are similar to the disparities that exist for Latinos more generally.

Policies aimed at reducing the number of uninsured Americans have led to a reduction in health disparities, especially for those with ongoing chronic health problem including cancer. Before the implementation of the ACA, many CCS lost their health insurance as they entered adulthood, eliminating a financial connection to the health care system. The expansion of coverage under the ACA closed...
that gap for many by providing more public and private options for CCS as young adults.\textsuperscript{31} Expanded coverage was particularly helpful for CCS who could now more easily obtain or retain insurance during the critical transitional period from pediatric to adult care.\textsuperscript{34}

The findings highlight the unique challenges faced by Latino cancer survivors in obtaining care for both cancer-related follow-up and non-cancer care.\textsuperscript{35,36} These contribute to the disparities in access to cancer survivorship services as well as lower rates of follow-up care observed among Latino CCS.\textsuperscript{37} Further research is needed among Latinos and other racial and ethnic CCS groups to understand the specific barriers to survivorship care among these at-risk populations.

As this study was conducted before the implementation of the ACA, the results provide information about the obstacles to care for low-income CCS when access to health insurance was more challenging. Thus, the findings provide a glimpse of what might happen if proposals to eliminate or modify the ACA are adopted, and CCS, who are now covered by ACA plans, might lose their health insurance.\textsuperscript{38} Dropping the Medicaid expansion is likely to create obstacles to care for low-income CCS, and young adults could once again face discrimination based on their history of cancer, face higher premiums, or be required to enter high-risk pools with unproven benefits.\textsuperscript{39}

Acknowledgments

The authors thank Kai-Ya Tsai, MS, MA, Anmol Shresth, and Sarah Jo who provided statistical, administrative, and editing support for this manuscript.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Support was provided by the Whittier Foundation, grant 1R01MD007801 from the National Institute on Minority Health and Health Disparities of the National Institutes of Health, and P30CA014089 from the National Cancer Institute of the National Institutes of Health. The collection of cancer incidence data used in this study was supported by the California Department of Public Health pursuant to California Health and Safety Code Section 103885; Centers for Disease Control and Prevention’s (CDC) National Program of Cancer Registries, under cooperative agreement 5N58DP003862-04/DP003862; and the National Cancer Institute’s Surveillance, Epidemiology and End Results Program under contract HHSN261201000014C awarded to the Cancer Prevention Institute of California and contract HHSN261201000035C awarded to the University of Southern California.

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References

1. Glied SA, Ma S, Borja A. Effect of the Affordable Care Act on Health Care Access. The Commonwealth Fund. https://www.commonwealthfund.org/publications/issue-briefs/2017/may/effect-affordable-care-act-health-care-access. Published May 8, 2017. Accessed August, 2018.

2. Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. J Clin Oncol. 2008;26(27):4401-4409.

3. Oeffinger KC, Mertens AC, Hudson MM, et al. Healthcare of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Ann Fam Med. 2004;2(1):61-70.

4. Lee JS, DuBois SG, Coccia PF, Bleyer A, Olin RL, Goldsby RE. Increased risk of second malignant neoplasms in adolescents and young adults with cancer. Cancer. 2016;122(1):116-123.

5. Aziz NM. Cancer survivorship research: state of knowledge, challenges and opportunities. Acta Oncol. 2007;46(4):437-442.

6. Ginsberg JP, Hobbie WL, Carlson CA, Meadows AT. Delivering long-term follow-up care to pediatric cancer survivors: transitional care issues. Pediatr Blood Cancer. 2017;46(2):169-173.

7. Lillie-Blanton M, Hoffman C. The role of health insurance coverage in reducing racial/ethnic disparities in health care. Health Aff (Millwood). 2005;24(2):398-408.

8. Markt SC, Lago-Hernandez CA, Miller RE, et al. Insurance status and disparities in disease presentation, treatment, and outcomes for men with germ cell tumors. Cancer. 2016;122(20):3127-3135.

9. Rong X, Yang W, Garzon-Muvdi T, et al. Influence of insurance status on survival of adults with glioblastoma multiforme: a population-based study. Cancer. 2017;122(20):3157-3165.

10. Smulowitz PB, O’Malley J, Yang X, Landon BE. Increased use of the emergency department after health care reform in Massachusetts. Ann Emerg Med. 2014;64(2):107-115.

11. Whittaker W, Anselmi L, Kristensen S, et al. Associations between extending access to primary care and emergency department visits: a difference-in-differences analysis. PLoS Med. 2016;13(9):e1002113.

12. Kuhlthau KA, Nipp RD, Shui A, et al. Health insurance coverage, care accessibility and affordability for adult survivors of childhood cancer: a cross-sectional study of a nationally representative database. J Cancer Surviv. 2016;10(6):964-971.

13. Milam JE, Meeske K, Slaughter RI, et al. Cancer-related follow-up care among Hispanic and non-Hispanic childhood cancer survivors: the Project Forward study. Cancer. 2015;121(4):605-613.

14. Gardner MH, Barnes MJ, Bopanna S, et al. Barriers to the use of psychosocial support services among adolescent and young adult survivors of pediatric cancer. J Adolesc Young Adult Oncol. 2014;3(3):112-116.

15. Keegan TH, Tao L, DeRouen MC, et al. Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers? J Cancer Surviv. 2014;8(2):282-292.

16. DeVoe JE, Tillotson CJ, Wallace L. S. Usual source of care for this manuscript.

17. Gardner MH, Barnes MJ, Bopanna S, et al. Barriers to the use of psychosocial support services among adolescent and young adult survivors of pediatric cancer. J Adolesc Young Adult Oncol. 2014;3(3):112-116.

18. Keegan TH, Tao L, DeRouen MC, et al. Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers? J Cancer Surviv. 2014;8(2):282-292.

19. DeVoe JE, Tillotson CJ, Wallace L. S. Usual source of care and nonurgent emergency department use. Acad Emerg Med. 2002;9(9):916-923.
18. United States Congress. Patient Protection and Affordable Care Act. H.R.3590. Public Law 111-148; 2010.
19. Miller KA, Wojcik KY, Ramirez CN, et al. Supporting long-term follow-up of young adult survivors of childhood cancer: correlates of healthcare self-efficacy. *Pediatr Blood Cancer*. 2016;64(2):358-363.
20. Harlan LC, Lynch CF, Keegan TH, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *J Cancer Surviv*. 2011;5(3):305-314.
21. Yin D, Morris C, Allen M, Cress R, Bates J, Liu L. Does socioeconomic disparity in cancer incidence vary across racial/ethnic groups? *Cancer Causes Control*. 2010;21(10):1721-1730.
22. Yang J, Schupp C, Harrati A, Clarke C, Keegan T, Gomez S. Developing an area-based socioeconomic measure from American Community Survey data. In: *Cancer Prevention Institute of California*. Published 2014. Accessed December 31, 2018.
23. Yost K, Perkins C, Cohen R, Morris C, Wright W. Socioeconomic status and breast cancer incidence in California for different race/ethnic groups. *Cancer Causes Control*. 2001;12(8):703-711.
24. Werba BE, Hobbie W, Kazak AE, Ittenbach RF, Reilly A, F, Meadows AT. Classifying the intensity of pediatric cancer treatment protocols: the intensity of treatment rating scale 2.0 (ITR-2). *Pediatr Blood Cancer*. 2007;48(7):673-677.
25. Kirby JB, Sharma R. The availability of community health center services and access to medical care. *Healthc (Amst)*. 2017;174-182.
26. Weinick RM, Quigley DD, Mayer LA, Sellers CD. Use of CAHPS patient experience surveys to assess the impact of health care innovations. *Jt Comm J Qual Patient Saf*. 2014;40(9):418-427.
27. Hudson MM, Kinahan K, Sharp LK, Freyer DR. Promoting health and care transitions in the long-term AYA survivor. In: Bleyer A, Barr R, Ries L, Whelan J, Ferrari A, eds. *Cancer in Adolescents and Young Adults (Pediatric Oncology)*. Cham, Switzerland: Springer; 2017.
28. Caplin DA, Smith KR, Ness KK, et al. Effect of population socioeconomic and health system factors on medical care of childhood cancer survivors: a report from the childhood cancer survivor study. *J Adolesc Young Adult Oncol*. 2017;6:74-82.
29. Tarazi WW, Bradley CJ, Harless DW, Bear HD, Sabik LM. Medicaid expansion and access to care among cancer survivors: a baseline overview. *J Cancer Surviv*. 2016;10(3):583-592.
30. Parsons HM, Schmidt M, Tenner LL, Bang H, Keegan TH. Early impact of the Patient Protection and Affordable Care Act on insurance among young adults with cancer: analysis of the dependent insurance provision. *Cancer*. 2016;122(11):1766-1773.
31. Sommers BD, Gunja MZ, Finegold K, Musco T. Changes in self-reported insurance coverage, access to care, and health under the Affordable Care Act. *JAMA*. 2015;314(4):366-374.
32. Leopold C, Park E, Nekhlyudov L. The impact of the Affordable Care Act on cancer survivorship. *Cancer J*. 2017;23(3):181-189.
33. Casillas J, Castellino SM, Hudson MM, et al. Impact of insurance type on survivor-focused and general preventive health care utilization in adult survivors of childhood cancer: the Childhood Cancer Survivor Study (CCSS). *Cancer*. 2011;117(9):1966-1975.
34. Jacobs LA, Shulman LN. Follow-up care of cancer survivors: challenges and solutions. *Lancet Oncol*. 2017;18(1):e19-e29.
35. Kaiser Family Foundation. *Health Reform*. Date unknown. http://kff.org/health-reform/. Accessed July 2018.
36. Kirchhoff AC, Lyles CR, Fluchel M, Wright J, Leisenring W. Limitations in health care access and utilization among long-term survivors of adolescent and young adult cancer. *Cancer*. 2012;118(23):5964-5972. doi:10.1002/cncr.27537.
37. Larson K, Cull WL, Racine AD, Olson LM. Trends in access to health care services for US children: 2000-2014. *Pediatrics*. 2016;138(6).
38. Liu L, Deapen D, Bernstein L. Socioeconomic status and cancers of the female breast and reproductive organs: a comparison across racial/ethnic populations in Los Angeles County, California (United States). *Cancer Causes Control*. 1998;9(4):369-380.
39. Perez GK, Kirchhoff AC, Recklitis C, et al. Mental health insurance access and utilization among childhood cancer survivors: a report from the childhood cancer survivor study. *J Cancer Surviv*. 2018;12(4):528-536.