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## Insurance, Chronic Health Conditions, and Utilization of Primary and Specialty Outpatient Services: A Childhood Cancer Survivor Study Report

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## Abstract

**Purpose:** Survivors of childhood cancer require life-long outpatient healthcare, which may be impacted by health insurance. This study sought to understand survivors' utilization of outpatient healthcare provider services.

**Methods:** The study examined cross-sectional survey data using an age-stratified sample from the Childhood Cancer Survivor Study of self-reported annual use of outpatient services.

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Multivariable logistic regression analyses were used to identify risk factors associated with utilization of services.

**Results:** 698 survivors were surveyed, median age 36.3 years (range 22.2–62.6), median time from diagnosis 28.8 years (range 23.1–41.7). Almost all (93%) of survivors had at least one outpatient visit during the previous year; 81% of these visits were with a primary care providers (PCP), 54.5% were with specialty care physicians, 30.3% were with nurse practitioner/physician's assistants (NP/PA), and 14.2% were with survivorship clinic providers. Survivors with severe to life-threatening chronic health conditions had greater odds of utilizing a specialty care physician (OR=5.15, 95% CI 2.89–9.17) or a survivor clinic (OR=2.93, 95% CI 1.18–7.26) than those with no chronic health conditions. Having health insurance increased the likelihood of seeking care from NP/PA (Private, OR=2.76, 95% CI 1.37–5.58; Public, OR=2.09, 95% CI 0.85–5.11), PCP (Private, OR=7.82, 95% CI 3.80–13.10; Public, OR=7.24, 95% CI 2.75–19.05), and specialty care (Private, OR=2.96, 95% CI 1.48–5.94; Public, OR=2.93, 95% CI 1.26–6.84) compared to without insurance.

**Conclusion:** Most childhood cancer survivors received outpatient care from PCP, but a minority received care from a survivorship clinic provider. Having health insurance increased the likelihood of outpatient care.

**Implications for Cancer Survivors:** Targeted interventions in the primary care setting may improve risk-based, survivor-focused care for this vulnerable population.

#### Keywords

cancer survivorship; health care delivery; health insurance; health status

## Introduction

Over the last fifty years, major therapeutic advances have transformed the field of pediatric oncology. Improvement in overall survival has made it possible for more than eight of every ten children diagnosed with cancer to become five-year survivors of their primary malignancy[1]. As of 2011, there were estimated to be over 388,000 childhood cancer survivors in the United States, a number which could approach 500,000 survivors by 2020[2,3]. Among these survivors, about 70% are over the age of 20 years[2]. It is imperative that primary care providers and specialists provide risk-based, survivor-focused care for childhood cancer survivors as they live into adulthood[4,5]. Such care is defined as a medical visit related to their prior cancer in which a screening test is discussed or ordered or the survivor is counseled on how to reduce his/her specific risks for late effects[5]. It is not clear how many childhood cancer survivors use or have access to this type of service within their primary care or speciality care follow-up arrangements.

Risk-based care is important for this vulnerable population in part because three quarters of long-term cancer survivors develop a chronic medical condition, with more than one-third suffering from a severe or life-threatening condition[6,7]. The rates of chronic medical conditions were found to be even higher than reported (95.5% for any chronic condition, 80.5% for severe or life-threatening) when systematic risk-based medical assessments were performed on a subset of survivors[8]. Consequently, survivor-focused, risk-based healthcare

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of aging adult survivors of childhood cancer should promote preventive care, early detection of late effects, and interventions to reduce morbidity or mortality of late effects of therapy[4,9].

While survivor-focused care may be provided in survivor-focused clinics, these specialized clinics may not be accessible to all survivors into adulthood. Survivor-focused care can be provided in many different settings including from a knowledgeable primary care physician (PCP) or nurse practitioner (NP); therefore understanding whom survivors are actually receiving care from will provide insights for understanding the best locus of care, and the need for future care coordination, and integration across primary and specialty care services.

Despite its importance, accessing primary or preventive services may be especially difficult for survivors because they may have difficulties obtaining adequate health insurance coverage. Multiple studies have documented the challenges faced by individuals with chronic illness in acquiring adequate and affordable health insurance coverage[10–15]. In 2005, Park et al. found that 29% of childhood cancer survivors reported having difficulty obtaining coverage as compared with a sibling cohort rate of only 3%[16]. The combination of a growing number of adult survivors of childhood cancer experiencing chronic medical conditions and lack or potential inadequacy of health insurance coverage poses a complex problem for the healthcare system. In 2012, the Affordable Care Act (ACA) incorporated new provisions into healthcare legislation to ensure coverage for those with pre-existing medical conditions and to improve their ability to obtain and maintain insurance[17]. Unfortunately, it is unclear whether proposals for ACA repeal and replacement will preserve the provisions intended to benefit childhood cancer survivors. Therefore, understanding the utilization of healthcare by survivors, and how healthcare patterns are influenced by insurance status, will be important for designing future guidelines that assure appropriate healthcare at affordable cost.

Park et al. conducted the "Long Term Follow Up: Health Insurance Study" survey in 2011–2012 as the ACA implementation was beginning[18]. In this publication, the investigators report on the utilization of outpatient healthcare services, including primary, specialty, and survivor-focused clinics by adult survivors of childhood cancer. The objectives were to quantify and describe outpatient healthcare utilization by adult survivors and identify survivor characteristics (chronic health conditions and insurance status) associated with outpatient healthcare utilization.

## Methods

## Study Design and Setting

This study was a cross-sectional survey administered as part of the Childhood Cancer Survivor Study (CCSS) performed between May 2011 and April 2012. All procedures were approved by the Institutional Review Boards of St. Jude Children's Research Hospital and the Massachusetts General Hospital/Partners HealthCare[18].

#### Study participants

The CCSS is a multi-institution, retrospective cohort with longitudinal follow-up, designed to investigate long-term outcomes in survivors of childhood cancer. Participants were initially diagnosed with childhood cancer at one of 26 institutions between 1970 and 1986, were younger than 21 years at diagnosis of leukemia, central nervous system malignancies, Hodgkin lymphoma, non-Hodgkin lymphoma, kidney cancer, neuroblastoma, soft tissue sarcoma or bone cancer, and survived greater than five years after diagnosis[19,20]. For this study, 1,101 survivors within the CCSS were randomly selected from three age strata (22–29 years, 30–39 years, 40 years). Of these, 698 survivors (70%) completed the paper- or webbased survey (see reference for CONSORT diagram)[18].

#### Measures

The survey instrument was designed utilizing information from an initial qualitative study[21] and national surveys[22–26] with pilot testing among adult childhood survivors treated at Massachusetts General Hospital. Two versions of the survey were administered (insured or uninsured) depending upon the response to the first survey question, "Do you currently have health insurance that covers doctor and hospital care?" (https:// ccss.stjude.org/tools-and-documents/questionnaires/original-cohort-questionnaires.html).

#### Participant demographic and clinical characteristics

Participant information was collected including sex, age at time of survey, race/ethnicity, current marital status, employment status, household income, and insurance characteristics. Treatment exposures were abstracted from medical records, and chronic health conditions were obtained from the CCSS follow-up 4 survey, administered in 2007[6,7,20]. Chronic health conditions were assigned severity scores based on the Common Terminology Criteria for Adverse Events (version 4.03, National Cancer Institute)[27]. The conditions were graded as mild (grade 1), moderate (grade 2), severe or disabling (grade 3), life-threatening (grade 4), or fatal (grade 5). For the analysis, chronic health conditions were categorized into mutually exclusive categories of: none, presence of any mild to moderate condition (grade 1–2), or presence of a severe to life-threatening condition (grade 3–4). Health insurance was classified as: private (including employer sponsored, military, or individual), public (including Medicare or Medicaid, but participant is not covered by a private insurance plan), and none.

#### Study Outcomes

Participants were asked a series of questions related to the outpatient healthcare they had received in the previous year, including which types of healthcare providers they had "seen or talked to for medical care (either routine or sick care)." Responses included: no outpatient visits, nurse practitioner/physician's assistant (NP/PA), primary care physician (PCP), specialty care physician, a provider who sees cancer survivors for routine follow-up care (e.g. survivorship clinic provider), or other (with fill-in space provided). Visits were analyzed based on whether there were seen by each type of provider (NP/PA, PCP, specialty care physician, survivorship clinic provider). Participants were also asked how many of their

visits were due to their previous illness of cancer; their responses were dichotomized to at least one due to previous illness versus none.

#### **Statistical Analysis**

All statistical analyses were performed using Stata version 13 (Stata, College Station, TX), incorporating weighting based on the distribution of age in the original CCSS cohort to achieve proportions representative of the entire original CCSS cohort[18]. Not all participants had complete data; those with missing data were not included in the logistic regression analyses. All p-values are two-sided and considered significant if less than 0.05.

Descriptive statistics were used to characterize demographic and clinical characteristics of survivors. The proportions of survivors who were evaluated by each type of outpatient healthcare provider were calculated, overall and by demographic and clinical characteristics. Frequency of visits to providers for those with at least one visit were determined. The investigators examined if there was an association between having a visit due to their previous cancer and which types of outpatient providers were seen. Separate weighted (i.e., on age at diagnosis) multivariable logistic regression were performed for each type of outpatient providers) treated as dichotomous outcomes to evaluate associated factors. Explanatory variables in regression modeling were selected *a priori* based on hypothesized clinical relevance and previous publications[5, 28, 29], which included: sex, health condition status, insurance status, patient age at time of survey, race/ethnicity, and household income.

## Results

#### **Participant Characteristics**

The majority of survivors were female and white/non-Hispanic (Table 1). Almost half of participants were between the ages of 40–62 years at the time of the survey. Leukemia was the most common primary cancer diagnosis. The median time since diagnosis was 28.8 years (range 23.1–41.7 years). 39.8% of survivors in this study had severe to life-threatening conditions, with 45.1% experiencing mild to moderate conditions; 15.1% did not report a chronic health condition. In terms of insurance, 10.3% of survivors did not have health insurance, 10.6% had public insurance, and 79% had private insurance.

#### **Outpatient Providers Seen by Childhood Cancer Survivors**

Respondents were also asked about their outpatient healthcare service utilization during the year prior to the survey, with 81.3% of survivors seen by a PCP, 54.5% seen by a specialty care physician, 30.3% seen by a NP/PA, and 14.2% seen by a survivorship clinic provider (Table 2). About a quarter (28.6%) of survivors were seen only by a PCP, 3.8% were seen only by a specialty care physician, and 0.6% were seen only by a survivorship clinic provider. Seven point two percent had no outpatient provider visits in the one-year timespan. For survivors with at least one outpatient visit, the median frequency of visits to a PCP was 2 (IQR 1–4, max 35), specialty care physician were 2 (IQR 1–4, max 40), and survivorship clinic provider were 0 (IQR 0–1, max 26). However, 27.2% of uninsured survivors received no outpatient healthcare in a year.

Higher proportions of female survivors were seen by each of the types of providers (NP/PA, PCP, specialty care physician, and survivorship clinic provider) as compared to males. For each different type of provider visits, survivors with severe to life-threatening chronic health conditions had higher proportions of seeking care compared to those with no conditions. Participants who indicated they were uninsured had the lowest proportion of seeking all types of providers compared to all other forms of known health insurance.

Nearly 40% of participants stated that at least one of their outpatient provider visits was related to their previous cancer. Survivors with at least one visit due to cancer had significantly higher proportions of visits to specialty care providers (77.2%) and survivor clinic providers (37.5%) than those with no visits due to their previous diagnosis of cancer (specialty care physician 50.6%; survivorship care provider 2.0%). There were no major differences for primary care providers (at least one visit due to cancer 89.4%, none due to cancer 91.3%).

#### **Factors Associated with Outpatient Provider Visits**

In multivariable analyses, female survivors were more likely than male survivors to have an outpatient provider visit with an NP/PA (OR=1.46, 95% CI 0.92–2.33) or specialty care providers (OR=1.54, 95% CI 1.07–2.22) compared to males (Table 3). Participants with mild to moderate chronic health conditions had a higher odds of a visit to a NP/PA (OR=2.07, 95% CI 1.13–3.79), a PCP (OR=2.29, 95% CI 1.20–4.36), and specialty care providers (OR=2.18, 95% CI 1.26–3.77) compared to those without chronic health conditions. Those with severe to life-threatening chronic health conditions had higher odds of a visit to a specialty care physician (OR=5.15, 95% CI 2.89–9.17) and to a survivor clinic (OR=2.93, 95% CI 1.18–7.26) compared to those with no chronic health conditions. Insured survivors had higher odds of having a visit with an NP/PA (Private, OR=2.76, 95% CI 1.37–5.58; Public, OR=2.09, 95% CI 0.85–5.11), a PCP (Private, OR=7.82, 95% CI 3.80–13.10; Public, OR=7.24, 95% CI 2.75–19.05), and a specialty care physician (Private, OR=2.96, 95% CI 1.48–5.94; Public, OR=2.93, 95% CI 1.26–6.84) compared to those without insurance.

## Discussion

In this study of outpatient healthcare utilization among childhood cancer survivors, it was found that nearly 40% of participants had at least one outpatient visit within the previous year that was related to their previous cancer. The vast majority of survivors (81.3%) were seen by a PCP, over half saw a specialist, but only 14.2% reported being seen at a survivorship clinic. While there are clear guidelines for the types and frequencies of risk-based screening and surveillance for childhood cancer survivors, the exact location of where this care is provided is not well outlined[29]. Limited evaluations among adult cancer survivors have not determined the most effective combination of care providers either[30]. This study suggests that the provision of the recommended risk-based, survivor-focused care may be most practically delivered by primary care providers who see the majority of adult survivors of childhood cancer.

The current literature among adult survivors of childhood cancer shows gaps in the receipt of survivor-focused care. For example, in an analysis of the baseline CCSS questionnaire,

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Oeffinger discovered that while 87% of survivors reported attending a "general medical visit," only 41.9% had received a "cancer-related visit" in the last two years[31]. Nathan et al. found that only 31.5% reported care that focused on their previous cancer, and only 17.8% reported survivor-focused care that included advice about risk reduction or discussion or ordering of screening tests[5]. Evidence suggests that primary care providers may be willing to provide long-term follow-up care, but many are not adequately prepared to provide survivor-focused care[32–34]. While the present study did not address survivor-focused care specifically, the investigators believe the finding that the majority of adult survivors of childhood cancer are receiving care by primary care providers, but not at survivorship clinics, seems to indicate that increased efforts should target survivor-focused care in the primary care setting. Therefore, multi-disciplinary approaches, such as the inclusion of a trained NP or PA, combined with patient engagement through survivorship care plans may be needed to achieve optimal care[6,35].

It also determined that about one-third of adult survivors of childhood cancer had a visit with an NP/PA in the last year. While this study was limited in the analysis due to the location of outpatient care provided by NP/PA's, their role in the care of adult survivors is important. Several studies have revealed that NP's are more likely to provide care in a wide range of community settings, including rural locations, suggesting that NP's could fill the survivorship care role if access to physicians is limited by geography[36,37]. An NP or PA who is knowledgeable in the follow up of survivors could play a large role in the provision of care that is required, but not currently being accomplished[5].

Care seeking should be determined by one's health status, presumably that survivors' healthcare utilization would correspond to their chronic health burden. While it was found that those survivors with chronic health conditions were more likely to seek services, gender and health insurance status were also significant factors. Specifically, survivors with insurance coverage had increased odds of having a visit to a PCP and a specialty care physician, suggesting that insurance coverage of any form may improve the receipt of outpatient care for survivors. Independent of the presence and grade of chronic health conditions, it was also found uninsured survivors are less likely than those with insurance to utilize outpatient medical providers. In recently published explorations of other aspects of the survey examined in this paper, Park et al. revealed that uninsured survivors experienced excess worry related to the cost of care, which translated into skipping or postponing medical care[38]. Those survivors with a higher percentage of income spent on out-ofpocket medical costs were also more likely to defer medical care or skip a test, treatment, or follow up[39]. While health status should drive the receipt of medical care, it is clear that the cost of care and presence of insurance contribute to achieving good access and utilization of healthcare services.

While this study adds insight into the outpatient healthcare utilization by childhood cancer survivors, there are several important limitations. Survivors' chronic health conditions, health insurance status, and types of providers seen were all self-reported. The types of outpatient providers seen does not necessarily determine the location of care, but it was assumed PCP's were seen in the primary care setting. Participants were also asked how many of the visits were related to their previous cancer, but this question was not specific to

the types of providers seen. There were no specific questions in this survey addressing if advice was provided or screening was performed specifically addressing cancer-related sequelae. This study did not intend to imply differences in the quality of care provided based on the types of providers seen by survivors of childhood cancer. The investigators acknowledge that references to prior CCSS publications are not independent from this study given the potential for overlap in sample populations. This survey was completed prior to the complete implementation of the ACA which likely impacted insurance coverage for this population[16]. Lastly, this study analyzed a cohort of survivors who were treated at tertiary care centers and included a limited number of racial or ethnic minorities, although the cohort is representative of survivors in the CCSS.

## Conclusion

In conclusion, the majority of childhood cancer survivors received care from primary care providers, but only 14.2% received care from a survivorship clinic provider. While the vast majority of survivors received outpatient healthcare over the one-year timespan studied, those with health insurance had much higher odds of receiving outpatient care by NP/PA, PCP, and specialty care physicians. While performed prior to complete implementation of the ACA, this analysis of outpatient healthcare utilization of survivors could be used to evaluate the impact of the ACA on actual healthcare utilization. Targeted interventions in the primary care setting may improve the rate of risk-based, survivor-focused care for this vulnerable population.

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#### Abbreviations:

ACA	Affordable Care Act
CCSS	Childhood Cancer Survivor Study
NP	Nurse Practitioner
PA	Physician Assistant
РСР	Primary Care Provider

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## Table 1.

## Demographic and Treatment Characteristics of Childhood Cancer Survivors

	N (Total = 698)	% (Weighted <sup>†</sup>
Age at survey, years		
22–29	214	11.3
30–39	228	42.3
40-62	256	46.2
Sex		
Female	384	54.5
Male	314	45.5
Race/Ethnicity*		
White, non-Hispanic	646	93.6
Black, non-Hispanic	14	1.7
Hispanic/Latino	24	3.0
Other	12	1.8
Education *		-
High school or less	98	14.1
Some college or more	179	26.8
Completed college and above	352	59.1
Marital Status*		
Single, never married	240	28.5
Married, living as married	393	61.3
Widowed/Divorced/Separated	59	10.2
Household Income*	-	
<\$20,000	91	12.0
\$20,000 - \$39,999	106	14.9
\$40,000 - \$59,999	104	15.8
\$60,000 - \$79,999	95	14.8
>=\$80,000	240	38.4
Don't know	36	4.2
Type of Cancer		-
Leukemia	255	35.0
Central Nervous System	104	14.9
Hodgkin lymphoma	71	12.9
Neuroblastoma	67	6.1
Wilms (Kidney) Tumor	66	8.1
Soft tissue sarcoma	51	8.3
Bone tumor	45	8.1
Non-Hodgkin lymphoma	39	6.7

	N (Total = 698)	% (Weighted <sup>†</sup> )			
Age at diagnosis, years					
0–5	404	46.4			
6–10	104	19.1			
11–15	109	19.8			
16–20	81	14.7			
Years since diagnosis, median (range)	28.8 (23	5.1–41.7)			
Recurrence of primary malignancy					
Yes	87	11.9			
No	611	88.1			
Subsequent neoplasm					
Yes	30	5.1			
No	668	94 9			
Chronic Health Conditions					
None	111	15.1			
Mild to moderate (CTCAE Grades 1-2)	319	45.1			
Severe to life-threatening (CTCAE Grades 3-4)	268	39.8			
Insurance					
Private	529	79.0			
Public	82	10.6			
None	79	10.3			

\* Totals and percentages provided only for survivors who reported on the indicated characteristic

 $^{\dagger}$ Percentages were weighted to reflect the population age distribution of the full original Childhood Cancer Survivor Study cohort;

CTCAE=Common Terminology Criteria for Adverse Events, Version 4.03

#### Table 2.

#### Outpatient Provider Visits by Childhood Cancer Survivors.

		Primary Care Physician N=556	Specialty Care Physician N=321	Nurse Practitioner/ Physician Assistant <sup>†</sup> N=208	Survivorship Clinic Provider N=97	No Outpatient Visits N=50		
	N		%* *					
Overall	698	81.3	54.4	30.3	14.2	7.2		
Age at survey, years								
22–29	214	76.5	51.1	29.1	13.1	7.0		
30–29	228	81.9	52.0	30.8	12.8	5.3		
40–62	256	81.9	57.3	30.0	15.8	9.1		
Sex	-							
Female	384	84.2	60.3	36.7	16.7	4.7		
Male	314	77.7	47.3	22.6	11.3	10.2		
Chronic Health Conditions								
None	111	70.9	30.1	19.8	8.0	16.5		
Mild to moderate	319	83.8	49.4	33.2	11.1	6.0		
Severe to life-threatening	268	82.4	69.2	31.0	20.1	5.0		
Insurance								
Private	529	86.1	57.7	32.2	13.8	5.3		
Public	82	85.3	58.6	31.3	21.0	2.8		
None	79	44.2	26.5	18.3	7.0	27.2		

Note: Columns are not mutually exclusive, percentages are by row to demonstrate the distribution of providers seen by independent characteristics

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

 ${}^{\dagger}$ Primary care versus specialty care location of Nurse Practitioner/Physician Assistant visits was not specified on the survey

#### Table 3.

## Factors Associated with Outpatient Provider Visits Among Childhood Cancer Survivors

	Primary Care Physician		Specialty Care Physician		Nurse Practitioner/ Physician Assistant		Survivor Clinic Provider	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Sex								
Female	1.46 (0.92–2.33)	0.11	1.54 (1.07–2.22)	0.02	1.86 (1.27–2.75)	0.002	1.46 (0.88–2.44)	0.14
Chronic Health Condition								
None	Reference		Reference		Reference		Reference	
Mild to Moderate	2.29 (1.20-4.36)	0.01	2.18 (1.26–3.77)	0.006	2.07 (1.13-3.79)	0.02	1.54 (0.61–3.90)	0.36
Severe to life-threatening	1.77 (0.92–3.40)	0.09	5.15 (2.89–9.17)	< 0.001	1.67 (0.90–3.12)	0.10	2.93 (1.18–7.26)	0.02
Insurance								
None	Reference		Reference		Reference		Reference	
Private	7.82 (3.80–13.10)	< 0.001	2.96 (1.48-5.94)	0.002	2.76 (1.37-5.58)	0.005	2.96 (0.95-9.23)	0.06
Public	7.24 (2.75–19.05)	< 0.001	2.93 (1.26-6.84)	0.01	2.09 (0.85-5.11)	0.11	3.57 (0.94–13.50)	0.06

Adjusted for: age at time of survey, race/ethnicity, household income