Cancer center-based follow-up among pediatric and adolescent/young adult cancer survivors: the role of a community-based organization and the social determinants of health

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Abstract

Purpose Adherence to survivorship care is suboptimal among pediatric and adolescent/young adult (AYA) cancer survivors. We evaluated predictors of cancer center-based follow-up among pediatric/AYA cancer survivors, with an emphasis on social determinants of health (SDOH).

Methods This retrospective cohort study used electronic health record data at an academic medical center to identify patients aged 0–29 years at last cancer treatment who completed treatment 2010–2019. Cancer center-based follow-up was defined by oncology or survivorship clinic visits through 12/31/2022. Multivariate logistic regression models (overall, ages 0–19 [pediatric], 20–29 [YA]) evaluated the association of demographics, clinical/treatment characteristics, and SDOH (insurance type, distance to cancer center, area deprivation index) with clinic attendance. Further modeling accounted for the service area of a community-based organization (CBO) that supports families of children with cancer.

Results A total of 2210 survivors were included (56% pediatric, 44% YA; 66% non-White). Cancer center-based follow-up decreased from 94% 1-year post-treatment to 35% at > 5–7 years. In adjusted analysis, AYAs had the lowest follow-up (5–7 years post-treatment: OR 0.25 [0.15–0.41] for age 25–29; OR 0.25 [0.16–0.41] for age 20–24; OR 0.32 [0.20–0.52] for age 15–19). Survivors residing within the CBO service area were twice as likely to follow-up (OR 2.10 [1.34–3.29]).

Conclusions Among a diverse population, AYA survivors were vulnerable to loss to follow-up. Other SDOH were not consistently associated with follow-up. Support from a CBO may partly explain these findings.

Implications for Cancer Survivors CBOs may strengthen survivorship follow-up within medically underserved communities. More research is needed to understand community support in survivorship.

Keywords Health disparities · Survivorship follow-up · Health equity · Community partnership

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Introduction

Advances in treatment for childhood cancer have dramatically increased the number of pediatric and adolescent/young adult (AYA) cancer survivors [1, 2]. It is estimated there are more than 500,000 survivors of childhood cancer in the USA [3]. This growing population has distinct healthcare needs due to their risk of health problems arising after completion of cancer therapy, referred to as late effects, which can lead to adverse medical, psychosocial, developmental, and functional outcomes. National and international guidelines recommend specialized survivorship care for pediatric/ AYA cancer survivors in order to detect and intervene on

late effects and improve health outcomes [4–6]. Despite evidence supporting the need for long-term follow-up, rates of survivorship follow-up remain low. Less than 20% of adult survivors of childhood cancer receive recommended risk-based survivorship care, with barriers to sustained follow-up existing at the survivor, provider, and healthcare system levels [3, 7, 8].

Progress in the field of cancer survivorship will require identifying the populations most vulnerable to loss to follow-up. This includes examining how access to follow-up care is impacted by structural racism — in which systems and policies have historically disadvantaged racial and ethnic minorities — and the social determinants of health (SDOH) — or the environmental conditions that affect health, including economic stability, neighborhood and built environment, social and community context, and healthcare access and quality [9–11]. Prior studies have investigated disparities in survivorship care by focusing on patient-level factors such as race/ethnicity, insurance, and rurality; however, the impact of these factors has differed across single-site cohort studies [12–16]. Prior studies have had limited racial/ethnic diversity, including a majority of non-Hispanic White patients [7, 12–16]. More recently, survivorship research has expanded beyond individual-level SDOH to include population-level measures of socioeconomic disadvantage, such as the area deprivation index (ADI), a composite measure of educational level, employment status, housing quality, and poverty measures at the Census block level [17, 18].

Current ongoing research aims to design and implement interventions to improve follow-up for vulnerable survivor populations [19, 20]. Outside of the research environment, community-based organizations (CBOs) deliver supportive services to patients with cancer before, during, and after treatment. An example is a nonprofit CBO that provides material and psychosocial support services to families of children with cancer in a rural 4-county region within our institutional cancer center's catchment area [21, 22]. The location and service area of the CBO in the context of our local geography and institutional catchment area are displayed in Supplemental Fig. 1.

Our institution in California provides a unique environment to investigate disparities in pediatric/AYA survivorship follow-up and the impact of SDOH, as it provides cancer care across a large geography to racially and socioeconomically diverse communities [23], and has a longitudinal partnership with a children's cancer support CBO. Our aim was to evaluate predictors of cancer center-based follow-up among pediatric/AYA cancer survivors. We sought to identify both risk factors and protective factors related to cancer center-based follow-up by examining associations with demographics and SDOH, including the role of a CBO in our community. We hypothesized that greater individual- and area-level socioeconomic disadvantage would be associated with lower rates of cancer center-based follow-up.

Methods

This retrospective cohort study used electronic health record (EHR) data at our institution to construct a cohort of pediatric/AYA cancer survivors. The Stanford Cancer Institute is a National Cancer Institute-designated Comprehensive Cancer Center which provides clinical care within Stanford Health Care and Stanford Children's Health (SCH). SCH is a pediatric healthcare system in the San Francisco Bay Area anchored by an academic, quaternary, free-standing children's hospital. Data extraction was completed through the Stanford Research Repository Tool (STARR), which provides aggregate clinical data generated from health system encounters that matches a defined clinical phenotype.

Criteria for cohort inclusion are detailed in Fig. 1 and included patients with a diagnosis code of malignancy present between January 1, 2010, and December 31, 2019, that were ≤ 29 years of age at last cancer treatment. Patients were excluded if (1) they did not receive any cancer treatment during this study period, to include only individuals who were treated at our institution; (2) they received cancer treatment in the clinical data extracted after 2019 (January 1, 2020–December 31, 2022); (3) they aged out of the AYA survivor definition, meaning they were > 29 years of age on the last day of treatment; or (4) they did not complete at least 1 cancer-related clinic visit in the 12 months prior to last treatment. These criteria were established to evaluate only patients who had completed cancer treatment and had not relapsed, and had not presented solely for second opinion. In order to exclude patients who moved away, we also removed patients who had a documented change in zip code to a region outside of California. Patients who died were included in the cohort through their death date, after which they were removed from analysis.

The primary outcome was cancer center-based follow-up, defined as completing at least one clinic visit in an oncology- or cancer survivorship-related department. We evaluated this outcome in two ways to understand how cancer center-based follow-up is sustained over time: (1) a time-based analysis assessing what fraction of the eligible cohort was seen for cancer center-based follow-up at least once in a period of time (0–1 year since last treatment date, > 1–3 years, > 3–5 years, and > 5–7 years) and (2) a comparative analysis that examined whether at least one cancer center-based clinic visit was completed during each of the studied time periods: 2–3 years and 5–7 years following a patient's last treatment date. We considered each time period independently, meaning that presence or absence of a clinic visit in one time period did not impact the results of the other time period. This allowed us to
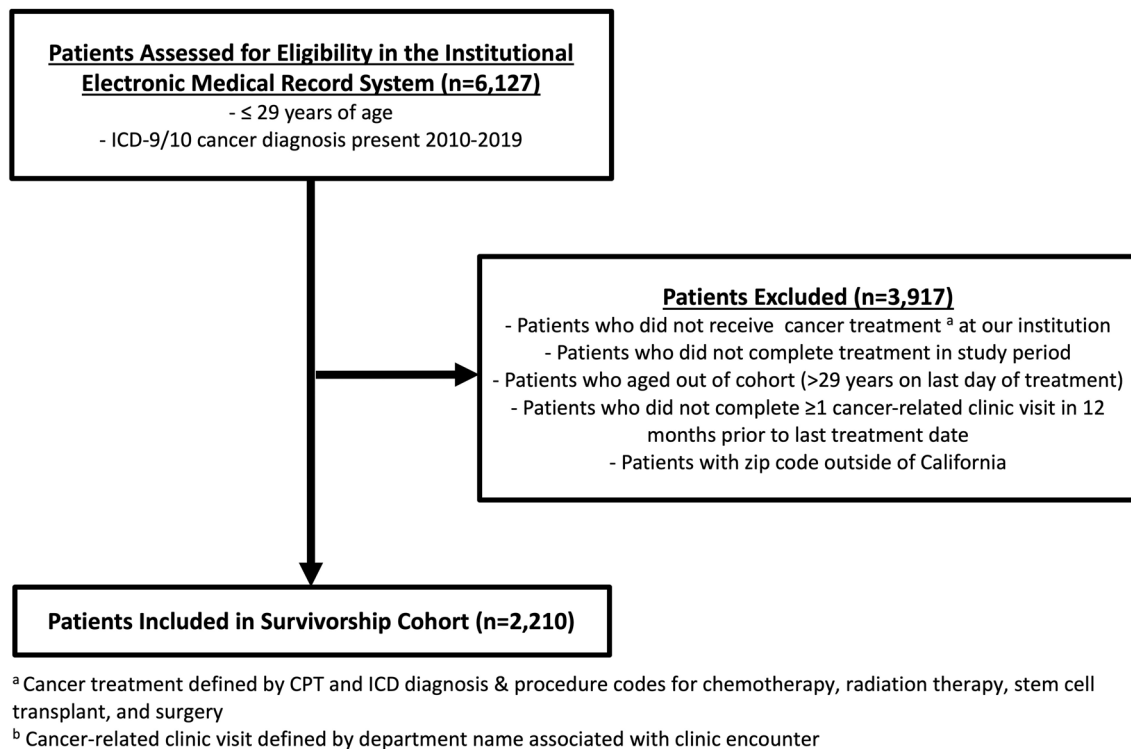
Patients Assessed for Eligibility in the Institutional Electronic Medical Record System (n=6,127)
- ≤ 29 years of age
- ICD-9/10 cancer diagnosis present 2010-2019

Patients Excluded (n=3,917)
- Patients who did not receive cancer treatment [a] at our institution
- Patients who did not complete treatment in study period
- Patients who aged out of cohort (>29 years on last day of treatment)
- Patients who did not complete ≥1 cancer-related clinic visit in 12 months prior to last treatment date
- Patients with zip code outside of California

Patients Included in Survivorship Cohort (n=2,210)

[a] Cancer treatment defined by CPT and ICD diagnosis & procedure codes for chemotherapy, radiation therapy, stem cell transplant, and surgery
[b] Cancer-related clinic visit defined by department name associated with clinic encounter

Fig. 1 Description of cohort construction

examine two distinct follow-up periods, one (2–3 years) representing early survivorship and the other (5–7 years) representing a later survivorship period when > 90% of pediatric oncology programs have transitioned patients to survivorship-focused long-term follow-up care [24].

Independent variables included age, sex, race/ethnicity, preferred language, insurance type, and distance to the cancer center. We categorized age at last treatment in 5-year increments to align with the National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) program's definition of childhood cancer as ages 0–19 and further divided our broad AYA age range of 15–29 into younger (15–19) and older (20–24, 25–29) age categories [25]. In some analyses, we present pediatric (0–19) and young adult (YA, 20–29) analyses separately to reflect healthcare system differences between the pediatric and adult cancer clinical programs. The age cut-offs between pediatric, adolescent, and young adult cancer patients are not consistently defined in the literature. Though some have extended the AYA age category to include those ≤ 39 years of age [26], we focused our study on ≤ 29 years of age to reflect a younger population where Children's Oncology Group guidelines for ongoing long-term follow-up care are more readily applicable [4]. Our study defines age in 5-year increments rather than as a continuous variable so that we could compare follow-up patterns among cancer survivors that completed treatment at distinct stages of childhood, adolescence, and young

adulthood, and also evaluate how these patterns evolved for survivors in each of these categories with increasing time since their cancer treatment.

Race/ethnicity was categorized as follows based on data available in the EHR: non-Hispanic White, Hispanic, Asian, non-Hispanic Black, Native Hawaiian or other Pacific Islander, other race/ethnicity, and unknown. It is important to recognize that there is a lack of standardization in how race and ethnicity are identified or categorized. Race and ethnicity are social constructs rather than biological or genetic descriptors, and should be interpreted in the context of other sociodemographic factors and social determinants and through the lens of structural and institutional racism [27, 28]. In our study, an additional race/ethnicity category was created to capture other and unknown races/ethnicities and those without adequate sample size (non-Hispanic Black, Native Hawaiian, or other Pacific Islander). Insurance type was extracted from EHR data though was notably limited as patient records only captured the latest insurance type listed on their most recent health encounter; we were unable to account for previous changes in insurance status and could not determine whether a patient's insurance type changed since their last listed encounter. Distance to the cancer center was calculated by distance between the center of a patient's zip code and the center of the cancer center's zip code. Area deprivation index is a measure of socioeconomic disadvantage

at the Census Block Group neighborhood level [29]. The 2019 ADI dataset was used in our analysis. For our analyses, ADI was normalized to the state of California and placed into three categories: least disadvantaged (deciles 1–2), somewhat disadvantaged (deciles 3–8), and most disadvantaged (deciles 9–10) in order to compare the regions with the greatest and least relative socioeconomic disadvantage. The International Classification of Diseases Clinical Modification (ICD-9-CM and ICD-10-CM) codes were used to group patients into cancer diagnosis categories. Treatment intensity was stratified into 4 levels using the Intensity of Treatment Rating Scale 3.0: least intensive (surgery only), moderately intensive (chemotherapy or radiation therapy), very intensive (2 or more treatment modalities), and most intensive (stem cell transplant) [30].

CBO coverage was defined based on zip code, as all pediatric patients living in a 4-county area are referred to the CBO at time of diagnosis. The CBO reports that nearly all families referred have accepted their support services; over the past 5 years, the proportion was 98.8%. The organization was founded in 1998 and its service area has not changed in the years during our study period. Though data linkage was not conducted across our institutional dataset and the CBO's internal database, the number of patients referred to the CBO over a 5-year period was similar to the number of patients in our dataset that lived in the CBO service area and completed treatment over a 5-year period. Additional descriptive comparisons of the CBO- and non-CBO-covered zip codes are described in Supplemental Table 1.

Categorical variables were reported with descriptive statistics (frequencies and percentages) and chi-square tests were used to assess for differences between proportions. A p-value ≤ 0.05 was deemed statistically significant. A line graph was constructed for the time-based analysis to visualize the proportion of the eligible cohort that was seen for cancer center-based follow-up at least once in each period of time after last cancer treatment: 0–1 year, > 1–3 years, > 3–5 years, and > 5–7 years. Univariate and multivariate logistic regression models were used to calculate odds ratios and 95% confidence limits for the dependent variables of completing cancer center-based follow-up at the two specified time periods (2–3 and 5–7 years post-treatment). Separate models were constructed to evaluate the survivorship cohort across all ages (0–29 years) as well as separately for pediatric (0–19 years) and YA (20–29 years) populations. Additionally, separate models were constructed with and without examining the presence of a CBO. Independent variables in the models were checked for multicollinearity; all models had variance inflation factors < 5 (ranges 1–1.22) indicating no collinearity. All statistical analyses were conducted using SAS version 9.4 (SAS Inc, Cary, NC) and graphs were designed in Microsoft Excel. This study was approved by the Stanford University Institutional Review Board.

Results

In total, 2210 pediatric/AYA cancer survivors met eligibility criteria. Among this survivorship cohort, 1240 patients (56%) were pediatric (0–19 years) and 970 (44%) were YA (20–29 years) at time of last treatment. Table 1 further describes the cohort demographics and characteristics.

Pediatric and AYA patients were both lost to follow-up with increasing time since last treatment. While 94% of patients were seen at a cancer-related clinic within the first year after treatment, only 61% of the cohort was seen > 1–3 years after treatment, and this decreased to 45% by > 3–5 years after and 35% by > 5–7 years after. Notably, this decline was steeper for AYA patients. Figure 2 depicts the rates of follow-up in the years since last treatment, stratified across different age categories among pediatric/AYA survivors.

For the first multivariate logistic regression model, we tested the association between the primary outcome of cancer center-based follow-up at 2–3 years and 5–7 years after last treatment and the survivorship and SDOH characteristics of interest. We additionally adjusted for sex, disease characteristics, and treatment exposures. The results of the multivariate logistic regression model are detailed in Table 2. In the overall cohort, increased age at last treatment was significantly associated with decreased odds of follow-up. At 2–3 years after treatment, survivors aged 25–29 were less likely to be seen for follow-up compared with the youngest survivors aged 0–4 (OR 0.31; 95% CI 0.20, 0.47). At 5–7 years after treatment, this gap increased (OR 0.25; 95% CI 0.15–0.41). This association remained significant for patients aged 20–24. A trend was seen whereby younger patients aged 10–14 and aged 15–19 did not have significantly decreased odds of follow-up in the 2–3 years after treatment, but did have decreased odds of follow-up by 5–7 years post-treatment. Multivariate regression results for the pediatric-only and YA-only cohorts are listed in Supplemental Table 2, with similar associations found for the two subsets compared to the overall cohort. Univariate regression results are shown in Supplemental Table 3 to describe each unadjusted association with cancer center-based follow-up without accounting for other covariates.

As detailed in Table 2, Hispanic and Asian patients did not have significant differences in odds of follow-up compared with non-Hispanic White patients at either time period. However, patients of additional race/ethnicity had decreased odds of follow-up (at 2–3 years after treatment, OR 0.60; 95% CI 0.44–0.82, at 5–7 years after treatment, OR 0.66; 95% CI 0.44–0.98). Among other SDOH in our model, patients with private insurance were more likely to follow-up in the later time point compared to those with

Table 1 Clinical and demographic characteristics of the cohort

	N	%
Total patients	2210	
Age at last treatment		
0–4 years	211	10
5–9 years	326	15
10–14 years	326	15
15–19 years	377	17
20–24 years	478	22
25–29 years	492	22
Sex		
Female	964	44
Male	1246	56
Race/ethnicity		
White, non-Hispanic	759	34
Hispanic	813	37
Asian	303	14
Black, non-Hispanic	30	1
Native Hawaiian or other Pacific Islander	3	0
Other	189	9
Unknown	113	5
Insurance type		
Public	925	42
Private	1225	55
Unknown	60	3
Primary language		
English	1886	85
Non-English	324	15
Distance from home to cancer center[a]		
Within 50 miles	1367	62
Within 50–100 miles	475	21
> 100 miles	368	17
Area deprivation index (ADI) categories[b]		
ADI least disadvantaged (deciles 1–2)	638	29
ADI somewhat disadvantaged (deciles 3–8)	1262	57
ADI most disadvantaged (deciles 9–10)	310	14
Cancer diagnosis		
Leukemia	736	33
Non-Hodgkin lymphoma	212	10
Hodgkin lymphoma	195	9
Central nervous system (CNS) tumors	364	16
Solid tumors (non-CNS)[c]	494	22
Other cancers	209	9
Treatment risk — Intensity of Treatment Rating Scale 3.0 (ITR-3)		
Least intensive (surgery only)	246	11
Moderately intensive (chemotherapy or radiation only)	1020	46
Very intensive (2 or more treatment modalities)	650	29
Most intensive (stem cell transplant)	294	13

[a]Distance from home to cancer center estimated based upon patient home address and cancer center zip codes

[b]Area deprivation index (ADI) is a composite measure of socioeconomic disadvantage based on income, education, employment, and housing quality, defined by zip code and normalized to California

[c]Solid tumors (non-CNS) include specified cancer types ≤ 5% individually including neuroblastoma, retinoblastoma, bone tumors, Wilms tumors, soft tissue sarcomas, breast cancers, cervical cancers, and testicular cancers
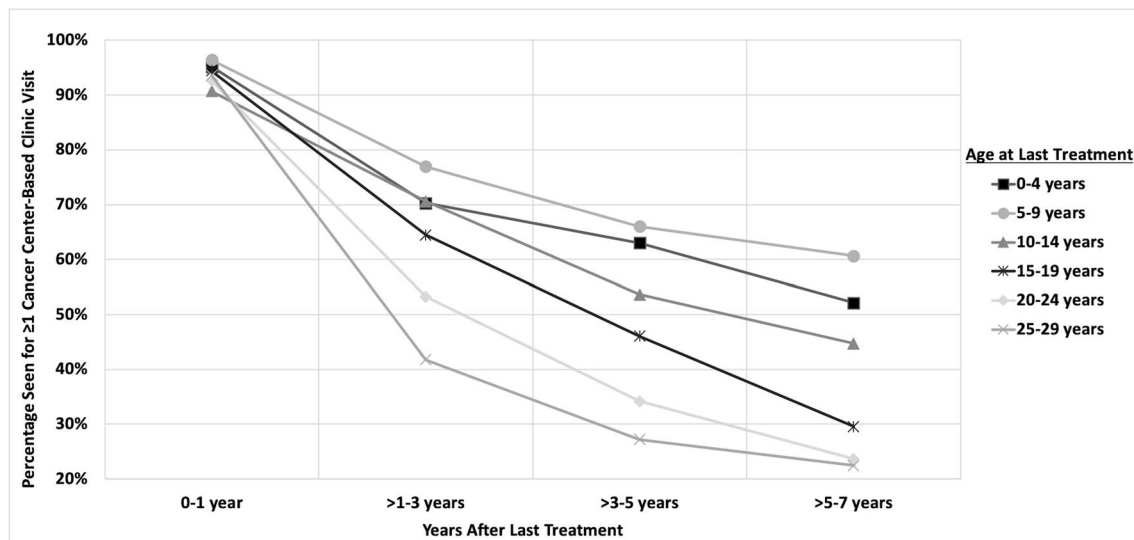
Fig. 2 Rates of cancer center-based follow-up by years since last treatment

public insurance (at 5–7 years after treatment, OR 1.37; 95% CI 1.04–1.82). Distance and primary language were not associated with cancer center-based follow-up. Notably, ADI was only found to be predictive of decreased follow-up among patients in the most disadvantaged group (highest 2 deciles) compared with patients in the least disadvantaged group (lowest 2 deciles) in the immediate 2–3 years after treatment (OR 0.56; 95% CI 0.35–0.88).

To further understand cohort differences, we compared survivors in our cohort that lived in CBO-serviced areas compared to those that did not. Patients living in areas serviced by the CBO were more likely to be disadvantaged: they were more likely to be publicly insured (57% CBO compared with 38% in non-CBO areas, $p < 0.001$), more likely to be Hispanic (54% CBO compared with 33% non-CBO, $p < 0.001$), and more likely to be non-English speaking (22% in CBO compared with 12% in non-CBO areas, $p < 0.001$). The mean ADI decile for CBO-serviced counties was 5.2 (standard deviation 1.98) compared with a mean ADI decile of 4.4 (standard deviation 2.93) in non-CBO-serviced counties. The results of the second multivariate regression model accounting for CBO service areas are detailed in Table 2, with the inclusion of only pediatric patients to reflect the CBO's focus on childhood cancer patients and survivors. Notably, survivors living in a zip code that was CBO-serviced were about twice as likely to be seen for follow-up compared with survivors living in zip codes that were not serviced by the CBO (at 2–3 years after treatment, OR 1.79; 95% CI 1.18–2.70; at 5–7 years after treatment, OR 2.10; 95% CI 1.34–3.29). Otherwise, similar associations were found to be significant between the pediatric-only cohort (detailed in Supplemental Table 2) and the same cohort when additionally accounting for CBO

coverage: older pediatric cancer survivors had decreased odds of follow-up at 5–7 years after treatment (ages 15–19: OR 0.31; 95% CI 0.19–0.51; ages 10–14: OR 0.57; 95% CI 0.35–0.92); patients of additional race/ethnicity had lower odds of follow-up at 2–3 years after treatment (OR 0.58; 95% CI 0.38–0.90); patients that were privately insured had higher odds of follow-up at 5–7 years after treatment (OR 1.45; 95% CI 1.01–2.09); and disadvantaged ADI was associated with lower odds of follow-up 2–3 years after treatment (ADI most disadvantaged: OR 0.39; 95% CI 0.21–0.75; ADI somewhat disadvantaged: OR 0.58; 95% CI 0.39–0.84).

Discussion

At our institution, pediatric/AYA cancer survivors had declining rates of cancer center-based follow-up as more time passed since their cancer treatment, with follow-up rates decreasing from 94% at 1 year after treatment completion to 61% by > 1–3 years and 35% by > 5–7 years. These rates are consistent with prior analyses of survivorship follow-up, which have focused primarily on the pediatric population; Daly et al. identified that 70% of pediatric patients attended their initial survivor clinic visit in the 2 years following treatment completion [15] and Zheng et al. found that < 30% of pediatric patients attended survivorship clinic at a 10-year post-diagnosis time point [14]. Our findings illustrate how cancer center-based follow-up decreases as survivors transition into the AYA age group: patients who completed cancer treatment at a younger age (aged 10–19) initially had no significant difference in cancer center-based follow-up compared with younger patients, but this changed at the later time point of 5–7 years after last treatment — the

Table 2 Adjusted multivariate logistic regression modeling for association between patient characteristics and odds of cancer center follow-up with and without community-based organization (CBO) coverage

	Overall cohort (0–29 years of age)		Model accounting for CBO coverage, pediatric-only cohort[a] (0–19 years of age)	
	OR at 2–3 years (95% CI)	OR at 5–7 years (95% CI)	OR at 2–3 years (95% CI)	OR at 5–7 years (95% CI)
Zip code serviced by CBO			**1.79 (1.18–2.70)**	**2.10 (1.34–3.29)**
Zip code not serviced by CBO			*(ref)*	*(ref)*
Age 25–29	**0.31 (0.20–0.47)**	**0.25 (0.15–0.41)**		
Age 20–24	**0.48 (0.31–0.73)**	**0.25 (0.16–0.41)**		
Age 15–19	0.65 (0.43–1.00)	**0.32 (0.20–0.52)**	0.66 (0.42–1.03)	**0.31 (0.19–0.51)**
Age 10–14	0.95 (0.62–1.48)	**0.55 (0.35–0.89)**	0.99 (0.63–1.54)	**0.57 (0.35–0.92)**
Age 5–9	1.41 (0.90–2.22)	1.00 (0.62–1.62)	1.38 (0.87–2.18)	0.92 (0.56–1.51)
Age 0–4	*(ref)*	*(ref)*	*(ref)*	*(ref)*
Hispanic race/ethnicity	1.18 (0.91–1.52)	1.27 (0.95–1.69)	1.15 (0.81–1.63)	1.26 (0.86–1.84)
Asian race/ethnicity	1.20 (0.85–1.70)	1.30 (0.87–1.96)	1.28 (0.80–2.05)	1.44 (0.85–2.44)
Additional race/ethnicity[b]	**0.60 (0.44–0.82)**	**0.66 (0.44–0.98)**	**0.58 (0.38–0.90)**	0.70 (0.42–1.18)
Non-Hispanic White race/ethnicity	*(ref)*	*(ref)*	*(ref)*	*(ref)*
Private insurance	1.06 (0.83–1.34)	**1.37 (1.04–1.82)**	0.99 (0.71–1.37)	**1.45 (1.01–2.09)**
Public insurance	*(ref)*	*(ref)*	*(ref)*	*(ref)*
English language	0.86 (0.61–1.21)	0.85 (0.58–1.26)	0.68 (0.44–1.05)	0.63 (0.39–1.01)
Non-English language	*(ref)*	*(ref)*	*(ref)*	*(ref)*
> 100 mi from cancer center[c]	0.73 (0.51–1.04)	0.73 (0.47–1.13)	0.79 (0.49–1.28)	0.70 (0.39–1.26)
51–100 mi from cancer center[c]	1.10 (0.81–1.49)	0.96 (0.68–1.36)	1.11 (0.72–1.71)	0.93 (0.58–1.50)
0–50 mi from cancer center[c]	*(ref)*	*(ref)*	*(ref)*	*(ref)*
ADI most disadvantaged[d]	**0.56 (0.35–0.88)**	0.62 (0.35–1.08)	**0.39 (0.21–0.75)**	0.54 (0.25–1.14)
ADI somewhat disadvantaged[d]	0.82 (0.62–1.07)	1.23 (0.90–1.68)	**0.58 (0.39–0.84)**	0.98 (0.65–1.47)
ADI least disadvantaged[d]	*(ref)*	*(ref)*	*(ref)*	*(ref)*

The multivariate regression models additionally adjusted for sex, cancer diagnosis, and treatment risk

[a]Model accounting for CBO coverage includes only the pediatric age cohort (0–19 years), as the CBO focuses its services on childhood cancer patients and survivors

[b]Additional race/ethnicity categories in study cohort included 9% other race/ethnicity, 5% unknown race/ethnicity, 1% Black non-Hispanic, and < 1% Native Hawaiian or other Pacific Islander

[c]Distance from home to cancer center estimated based upon patient home address and cancer center zip codes

[d]Area deprivation index (ADI) is a composite measure of socioeconomic disadvantage based on income, education, employment, and housing quality, defined by zip code. Most disadvantaged corresponded to ADI deciles 9–10, somewhat disadvantaged to ADI deciles 3–8, and least disadvantaged to ADI deciles 1–2

time period when most of these patients would have aged into young adulthood. Further research is needed to illuminate whether the decrement in cancer center-based follow-up is due to transitioning to survivorship care elsewhere or loss of survivorship care altogether.

In this study, we saw the strongest associations between increased age at last treatment and loss of cancer center-based follow-up. Otherwise, our systems of care appeared to overcome some but not all insurance-, distance-, and language-related barriers to follow-up care, similar to prior research [12, 16, 31]. Private insurance was associated with increased follow-up compared to public insurance only at the later timepoint of 5–7 years since treatment completion. Although this reinforces previous work showing better follow-up care for survivors with private insurance [32], interpretation of this finding is limited by the inability of our data to track insurance changes over time. Distance and language were not associated with follow-up. Interestingly, in our study, ADI was associated with lower cancer center-based follow-up more immediately in the 2–3 years after treatment completion when comparing the most and least disadvantaged zip codes. However, this trend did not persist in the later time point of 5–7 years after treatment, where no significant differences were seen for patients in the most or somewhat disadvantaged zip codes compared with those in the least disadvantaged zip codes. These findings add to prior childhood cancer survivorship studies that have evaluated the role of ADI in survivorship outcomes. Noyd et al.

constructed a similar single-institution cohort and found in univariate analyses that pediatric hematology-oncology and pediatric neuro-oncology survivors seen in any oncology-related subspecialty clinic at the institution 5–7 years after initial diagnosis had a mean ADI percentile that was lower (meaning lesser neighborhood-level disadvantage) compared to survivors that were not seen in clinic in that time frame [17]. Ehrhardt et al. found in multivariate analyses of adult survivors of childhood cancer in the St. Jude Lifetime Cohort that living in a census block with a high ADI (most disadvantaged) was associated with increased risk of late all-cause or health-related death [18]. Our findings offer an example wherein differences in area deprivation were not consistently associated with disparities in survivorship outcomes. While neighborhood-level metrics such as ADI are useful as a broad approximate of regional advantages, they fail to capture local features that additionally determine health outcomes — as our study found upon incorporating regional CBO presence.

One factor unique to our local environment was the presence of a childhood cancer CBO that has serviced part of our cancer center catchment region for 25 years. Our study assessed what the long-term impacts of CBO presence may have on a region and found that living in a CBO service area was significantly associated with increased cancer center-based follow-up. These associative analyses offer one method by which to examine the relationship between community support and survivorship outcomes. This approach builds on previous studies of community partnerships that have primarily described the design and assessment of community-based interventions [19, 20]. Our study highlights the impact of a community-level resource in a region that by other measures would be considered as vulnerable to health disparities. These findings may reflect the importance of CBOs as trusted liaisons for healthcare access and education, similar to the efficacy of *promotores de salud* (community health workers) in increasing healthcare engagement, education, and outreach for racial/ethnic minority populations [33]. Further work is needed to demonstrate the impact of community support on survivorship experiences and their importance in healthcare coordination and delivery, particularly in communities historically impacted by the structural inequities of healthcare.

Conducting this study in California enabled us to assess for racial/ethnic disparities in cancer center-based follow-up among a higher minority patient population than previously published literature. Prior studies that have identified racial disparities in survivorship follow-up have primarily reported decreased follow-up among non-Hispanic Black or aggregated non-White pediatric cancer survivors and drawn these conclusions from cohorts that have been > 69% non-Hispanic White [7, 12, 13, 17], compared to our cohort that was only 34% non-Hispanic White. Our study is the first

to examine associations between race/ethnicity and survivorship follow-up among a large Hispanic (37%) and Asian (14%) survivor population. Hispanic and Asian patients had no differences in cancer center-based follow-up compared to non-Hispanic White patients, while patients in the additional race/ethnicity category had decreased likelihood of follow-up at both time points. It is difficult to draw meaningful conclusions from this finding as this is a heterogenous group that included predominantly patients with "other" and "unknown" race/ethnicity (due to limitations of EHR capture of race/ethnicity data) and low numbers of non-Hispanic Black and Native Hawaiian or other Pacific Islander patients. Overall, our study offers a first look at racial/ethnic disparities in survivorship care among a large Hispanic and Asian patient population, while highlighting the need for greater inclusion of minority cancer survivors in research on survivorship inequities.

The findings from this study must be considered in the context of its limitations. First, we used cancer center-based follow-up, defined by completed visits within oncology or survivorship clinics, to approximate survivorship follow-up, because survivorship is almost always embedded within the oncology clinic at our cancer center. It is possible that some survivors could have obtained survivorship care outside of our cancer center, for example, through primary care clinics. It is also possible that some survivors transferred care to a different medical center and could have been receiving appropriate survivorship follow-up elsewhere. However, literature suggests that a majority of AYA patients prefer continuing to see their oncologist for follow-up care [34], and a report on transition practices by Children's Oncology Group institutions illustrates high variability in models of survivorship care for young adult survivors of childhood cancer: only 34% of patients transferred to a primary care provider, while 34% continued to be seen indefinitely at the pediatric center/treating institution, 14% transferred to adult oncology or survivorship, and 5% transferred to a survivorship specialty clinic [35]. These transitions in survivorship care from pediatric to adult long-term follow-up remain complicated and variable, and ongoing work is investigating the models, facilitators, and barriers of this process [36, 37]. Our EHR data encompasses records from both the pediatric and adult health systems; thus, AYA patients who transferred to adult oncology or survivorship would have been captured in our analyses. This was a single-center study and the distribution of patients seen at our cancer center may not be reflective of the broader pediatric/AYA cancer survivor population, limiting study generalizability.

Utilizing EHR data also has its inherent limitations: there is a need to improve accurate documentation of race/ethnicity, language preference, and parent occupation in EHRs [38]. Additionally, our EHR only reflects a patient's insurance status at the time of the most recent clinical encounter,

and fails to capture changes in insurance type over time. Other studies have more rigorously scrutinized the role of insurance coverage in survivorship care [32, 39]. This work has implications for healthcare policy, as countries with single payer systems and better integration between specialty and primary care services may have more shared financial incentives to support cancer survivorship care, in contrast to health systems in the USA that have fewer incentives for preventative care and efficient healthcare utilization [40, 41]. These questions are beyond the scope of our work but remain ripe for further study. Lastly, our study was not able to directly link institutional EHR data and CBO data records; future clinic–community data linkages could enable more granular evaluation of the impact of community-based support on healthcare practices.

Conclusion

This study evaluated predictors of cancer center-based follow-up among a diverse cohort of pediatric/AYA cancer survivors at an institution that provides cancer care to a racially and socioeconomically heterogenous population across a large geography. Our findings reinforce previous studies that highlight the AYA survivor population as one that is prone to loss to follow-up: in our study population, decreased follow-up was seen for AYA cancer survivors as well as pediatric cancer survivors as they aged into young adulthood. Additionally, we evaluated survivorship disparities in a pediatric/AYA survivor cohort with a larger proportion of minority patients than previously published literature; associations between minority race/ethnicity, other SDOH, and cancer center-based follow-up care were mixed. Further analysis revealed that community-based organizations may play a role in promoting care: patients living in regions serviced by a CBO were over twice as likely to have cancer center-based care in the years after treatment. This is the first study to date that examines the role of a CBO on follow-up care for cancer survivors. These findings have implications for the field of cancer survivorship, highlighting the important role of community-based cancer support organizations and the potential for community-academic partnerships to advance research and clinical care for cancer survivors.

Declarations

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