

# Hawai'i's Multiethnic Adolescent and Young Adult Survivors of Childhood Cancer: Are Their Health Behavior Risks Similar to State and National Samples?

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## Abstract

*Due to toxicities associated with their malignancies and treatments, adolescent and young adult survivors of childhood cancer (AYASCC) are at high risk for developing chronic diseases. This can be compounded by a greater prevalence of unhealthy behaviors relative to similarly aged non-cancer peers. Disparities in health behaviors have been noted for Black and Hispanic AYASCC, but data on Asian American (AA) or Native Hawaiian and Other Pacific Islander (NHOPI) minorities are lacking. The purpose of this study was to help bridge these information gaps by gathering data from Hawai'i AA and NHOPI AYASCC. Telephone surveys were used to collect health behavior data from survivors 13-24 years of age (N=64); 55% of the sample was female, 77% AA or NHOPI, 63% leukemia/lymphoma survivors, and 32% overweight/obese. These were compared to state/national survey data for similarly aged individuals (Youth Risk Behavior Surveillance System data for 13-17 year olds, and Behavioral Risk Factor Surveillance System data for 18-24 year olds). While Hawai'i AYASCC had significantly lower rates of tobacco/alcohol use, a higher proportion did not eat five fruits/vegetables a day (96%) compared to state (83%) and national (78%) samples ( $P < .001$ ). Although many met age-specific physical activity recommendations, 44% of <18 year olds and 29% of  $\geq 18$  year olds still failed to meet national guidelines. Low intake of fruits/vegetables and suboptimal levels of physical activity place these vulnerable, ethnic minority cancer survivors at higher risk for chronic disease. These findings underscore the need to assess and advise survivors about their diet and exercise habits as part of post-treatment care.*

## Keywords

Childhood cancer survivors; Asian and Native Hawaiian/Pacific Islander; Nutrition; Physical activity

## Introduction

Due to advances in therapy over the last 30 years, five-year survival rates for children afflicted with cancer are high (70% - 80%), and these rates are sustained for up to 20 years after diagnosis.<sup>1,2</sup> Thus, the majority of pediatric cancer patients are likely to live many years after their therapy ends. However, due to the added burden of toxicities associated with their primary malignancies and treatments,<sup>3-5</sup> adolescent and young adult survivors of childhood cancer (AYASCC) are at increased risk for development of chronic diseases relative to the general population.<sup>6</sup>

While a healthy lifestyle can mitigate the severity of these problems, results from the National Cancer Institute (NCI) funded Childhood Cancer Survivor Study (CCSS) and the Children's Oncology Group (COG) revealed a disconcertingly high incidence of tobacco and alcohol use as well as physical inactivity among AYASCC.<sup>7-11</sup> The CCSS reports are from a multi-institutional (N=26 institutions) study of children (less than 21 years of age) who survived 5 years or more after being treated between 1970-1986 for specific types of cancer including leukemia, brain tumor, Hodgkins lymphoma, non-Hodgkins lymphoma, etc.<sup>12</sup> A detailed description of eligibility and survey

methods used in the CCSS cohort is available elsewhere.<sup>12-14</sup> The COG is a NCI funded clinical trials group devoted to childhood and adolescent cancer research conducted at over 200 children's hospitals, universities, and cancer centers across the United States and in foreign countries.<sup>10,15,16</sup> A study investigating the high risk behaviors of 117 childhood survivors of leukemia, previously treated in COG trials but who are currently young adults, found that 22% percent had smoked cigarettes in the last 30 days and 25% reported binge drinking in the last month.<sup>10</sup> A 2009 study by Tai and colleagues identified survivors of childhood cancer who participated, as adults, in the Behavioral Risk Factor Surveillance System (BRFSS) survey, and found that the childhood cancer survivors had significantly higher rates of smoking, obesity, heart disease, hypertension, and diabetes compared to respondents with no history of cancer.<sup>6</sup> A recent COG study of adult survivors of childhood cancer found they had high prevalence rates for adverse health outcomes related to pulmonary, auditory, reproductive, cardiac, and neurocognitive disorders/abnormal function.<sup>17</sup> Another recent single institution study showed that adolescents and young adult survivors reported significantly poorer health related quality of life than both the general population and those diagnosed at an earlier age. In addition, a significant proportion also failed to meet national recommendations for fruit and vegetable intake (76%), energy from fat (39%), fiber intake (96%), and physical activity (65%).<sup>18</sup> It is therefore disconcerting that although most childhood cancer survivors receive post-therapy medical care, only 18% of these encounters involved discussion of risk-based screening or counseling on behavioral changes to reduce risk.<sup>11,19</sup> Nevertheless, data indicate that survivors in the most at-risk subgroups are generally more interested in participating in diet and physical activity interventions, suggesting the benefit of future research to develop interventions in these areas.<sup>18</sup>

Disparities in health behaviors exist by race/ethnicity among AYASCC. The (2003) CCSS survey found that more AYASCC black survivors, compared to white, Hispanic or "other races/ethnicities," were not meeting national guidelines for physical activity.<sup>7</sup> There is a lack of granularity with respect to these "other races/ethnicities," including Asian Americans (AA), Native Hawaiians, and Other Pacific Islanders (NHOPI), where cultural or social factors can contribute significantly to health behaviors. For example, Lowry and colleagues combined the data from four nationally representative samples of United States high school students surveyed in the 2001, 2003, 2005, and 2007 Youth Risk Behavior Surveillance System (YRBSS). They found that AA were significantly less likely than black, Hispanic, or white students to have drunk alcohol, used marijuana,

or be currently sexually active; while NHOPI were much more likely than other ethnic groups to have contemplated suicide.<sup>20</sup> However, due to low numbers of AA and NHOPI in the CCSS national cohort study of AYASCC, their data are listed under the “other” race/ethnicity category and are not typically included in the statistical analyses for ethnic minorities. Thus, most of our current understanding has been gleaned from analyses of largely Caucasian populations, and there is practically nothing published about the prevalence of adverse health behaviors among AYASCC of AA or NHOPI ancestry.<sup>7,18,21,22</sup>

This study was undertaken to help bridge information gaps about AA and NHOPI AYASCC in Hawai‘i, specifically to see if they had a higher prevalence of selected adverse health behaviors than similarly aged representative samples from Hawai‘i and across the United States.<sup>6,9,11,23</sup>

## Methods

### Study Design

This study was a cross-sectional telephone survey of AYASCC from a children’s cancer clinic on O‘ahu, and all surveys and protocols were approved by the institutional review board of Kapi‘olani Medical Center for Women and Children (KMCWC; RP#07-006-1HPH2).

### Eligibility and Enrollment

AYASCC patients who were diagnosed and treated from 1983 to 2008 at KMCWC and were between the ages of 13–24 years at the time the study was conducted, at least one month post-treatment, and could speak English were eligible. KMCWC providers at the cancer clinic pre-screened potentially eligible AYASCC and removed those patients who were currently in treatment, had moved or lived out of state, died, or who were still recovering from recent cancer therapy. The telephone surveys were conducted from 2007–2008. Parents of potentially eligible patients were mailed a recruitment letter along with a HIPAA (Health Insurance Portability and Accountability Act) consent and assent forms granting permission to access information in the patient’s medical records and to participate in a telephone survey. A “do not contact” postcard was also included for uninterested parents or patients. Research staff called non-responders two weeks after the mailing to assess their interest in the study.

### Data Collection

Different age-specific surveys for AYASCC < 18 years old and ≥ 18 years old were used to assess health behaviors: the YRBSS for high school students, and the BRFSS for adults > 18 years of age.<sup>24,25</sup> Only selected questions on alcohol and tobacco use, physical activity, and fruit/vegetable intake were administered, as opposed to the entire YRBSS or BRFSS surveys. Verbatim questions from the YRBSS were slightly modified for administration via a telephone interview, so as to maintain the privacy of the youth answering at home (eg, questions were read to the respondent but there were no probing or follow-up questions, nor insistence on a reply, ie, respondents could answer “don’t

know” or “prefer not to answer”). The BRFSS and YRBSS questions used in this study are available, on request, from the first author.

### Comparison Samples

Age-matched results from our sample were compared to state-wide and national surveys (for YRBSS < 18 years and BRFSS for ≥ 18 years). We downloaded (using the CDC online tool) United States and Hawai‘i YRBSS (high school) prevalence data for a specific question and compared it to our < 18 years old AYASCC sample’s percentages. We used a similar online tool to download the prevalence data for 18–24 year old adults who completed the United States and Hawai‘i BRFSS, and compared their prevalence data to our 18–24 year old AYASCC.<sup>26,27</sup> Data from the 2005 or 2007 national surveys were used if available; otherwise data from the most recent previous year were used and noted in the results. Our sample of < 18 year old survivors had a proportion of AA and NHOPI (70%) that was comparable to the 2007 Hawai‘i YRBSS sample of 79% AA or NHOPI described in analyses conducted by Eaton and colleagues.<sup>28</sup>

### Statistical Methods

Statistical analyses were done using SAS (version 9.2; SAS Institute Inc., Cary, NC). Comparisons with state, national, and other research data were conducted using Chi-square analyses, Fisher’s exact tests, t-tests, and two proportion z-tests.<sup>29</sup>

## Results

### Patient Characteristics

Of the 332 patients diagnosed from 1983–2008 who were between 13 and 24 years at the time of the study, 215 patients (64.8%) were potentially eligible and sent recruitment letters. Very few (4%) returned the “do not contact” postcard. One-fifth (20%) of the letters were returned undeliverable, and 3% were determined to be ineligible during follow-up contacts. No response was provided by 43%. Thus, the positive response rate was 29.8% (64 of 215 contacted). There was no difference between the proportion of respondents versus non respondents by age group (< 18 or ≥ 18 years old). Regardless of age, females were significantly more likely to participate than males (40.9% vs 22.8%,  $P = .006$ ). There were no significant differences between the proportion of respondents versus non-respondents by race (white versus non-white) or cancer diagnosis. The total sample (Table 1) had a mean age of  $18.9 \pm 3.4$  years, and 36% of the sample was < 18 years, with 19% white, 47% AA, 30% NHOPI, 2% African American, and 3% other. Most had leukemia or lymphoma, with an average of  $9.1 \pm 5.3$  years since diagnosis, and many (66%) used state or federal insurance. About a third (32%) of the total sample was classified as overweight or obese according to age-specific criteria.

### Health Risk Behaviors

The AYASCC < 18 (13–17 years old) reported fewer risk behaviors than the YRBS samples from both Hawai‘i and nationwide (see Table 2).<sup>28,30,31</sup> Only one (4%) AYASCC had

Table 1. Demographic Characteristics of Adolescent and Young Adults Survivors of Childhood Cancer in Hawai'i			
	Total Sample	<18 years	≥18 years
Total N	64	23	41
Mean Age (years ± S.D.)	18.9 ± 3.4	15.3 ± 1.5	20.9 ± 2.3
Age Range (years)	13-24	13-17	18-24
Gender n (%)			
Female	35 (55)	13 (57)	22 (54)
Male	29 (45)	10 (44)	19 (46)
Ethnicity n (%)			
Hispanic	10 (16)	5 (23)	5 (12)
Non-Hispanic	54 (84)	18 (78)	36 (88)
Race n (%)			
Asian	30 (47)	11 (47)	19 (46)
White	12 (19)	7 (30)	5 (12)
Native Hawaiian or Pacific Islander	19 (30)	5 (22)	14 (34)
African-American	1 (2)	0 (0)	1 (2)
Other	2 (3)	0 (0)	2 (5)
Cancer diagnosis* n (%)			
Leukemia, Lymphoma	40 (64)	15 (68)	25 (61)
Brain tumor	6 (10)	1 (5)	5 (12)
Solid tumor (extracranial)	16 (25)	5 (23)	11 (27)
Other	1 (2)	1 (5)	0 (0)
Time since diagnosis (years ± S.D.)*	9.1 ± 5.3	7.6 ± 3.4	9.9 ± 6.0
Body Mass Index (BMI kg/m <sup>2</sup> )*	23.9 ± 5.4	22.4 ± 5.0	24.7 ± 5.5

\*One cancer Dx, one time since diagnosis, and one BMI were missing

Table 2. Behavioral Risk Factors among AYASCC 13-17 Years and similarly aged Hawai'i/National representative samples					
	13-17 Yrs AYASCC Sample (n=23)	High School YRBS Hawai'i (n=1,191)	P-value*	High School YRBS United States (n=13,840)	P-value**
<b>Tobacco Use</b>					
Ever tried cigarette smoking	4 %	67.2% <sup>†</sup>	< .001	50.3%	< .001
Smoked a cigarette in last 30 days	0.0%	27.9% <sup>†</sup>	< .001	20.0%	< .001
<b>Alcohol Use</b>					
Ever had a drink of alcohol	9%	58.7%	< .001	75.0%	< .001
Had 1 drink in last 30 days	4 %	29.1%	< .001	44.7%	< .001
<b>Nutrition</b>					
Did not eat ≥ 5 fruits/vegetables per day	96%	82.8%	< .001	78.6%	< .001
<b>Physical Activity</b>					
NotActive ≥ 60 min/day for ≥ 5 days in last week	44%	65.7%	< .001	65.3%	< .001
Did not play on sports team in past 12 mo	52 %	45.4% <sup>†</sup>	.052	43.7% <sup>†</sup>	.013

\*Comparison of sample to state YRBS data; \*\*Comparison of sample to national YRBS data; <sup>†</sup> Data from 1999 YRBS

Table 3. Behavioral Risk Factors among AYASCC 18-24 Years and similarly aged Hawai'i/National representative samples					
	18-24 Years AYASCC Sample (n=41)	18-24 years BRFSS Hawai'i (n=319)	P-value*	18-24 years BRFSS United States (n=15,396)	P-value**
<b>Tobacco Use</b>					
Smoked ≥100 cigarettes in entire life	21 %	32.4%	0.004	31.5%	0.004
Current smoker†	0%	66.9%	<0. 001	75.6%	<0. 001
<b>Alcohol Use</b>					
Had 1 drink in last 30 days	44%	52.6%	0.009	52.2%	0.004
Average drinks per drinking day††	4.88	4.29	0.66	3.84	0.514
<b>Nutrition</b>					
Did not eat ≥5 fruits/vegetables per day	78 %	73.1%	0.105	73.4%	0.086
<b>Physical Activity</b>					
Did not meet recommendations for physical activity (ie, > 150 minutes of moderate to vigorous physical activity per week)	29 %	41.1%	<0. 001	45.1%	<0. 001

\*Comparison of sample to state BRFSS data; \*\*Comparison of sample to national BRFSS data; †Now smoke every day or some days, of those who have smoked ≥100 cigarettes in entire life; ††Of those who drank in last 30 days.

ever tried smoking, compared to 67.2% and 50.3% of the state and national YRBS samples, respectively. Likewise, alcohol consumption rates were lower among AYASCC, with only 9% reporting that they had ever drunk alcohol compared to 58.7% of the Hawai'i and 75% of United States YRBSS samples. All of these comparisons were statistically significant, with *P*-values <.001. AYASCC <age 18 were more likely to be physically active than the state and United States YRBSS samples <18 years of age. However, nearly all AYASCC (96%) ate fruit/vegetable fewer than 5 times per day, compared to 82.8% in the Hawai'i and 78.6% national YRBS samples (*P* <.001 for both). Results for AYASCC >18 (18-24 years) are shown in Table 3. Relative to respondents to the BRFSS national survey, they were significantly less likely to have smoked ≥100 cigarettes in their entire life, to be a current smoker, and to have had a drink in the past 30 days. A larger proportion (78%) reported eating fruit/vegetables less than 5 times per day compared to the state and national BRFSS samples (73.1% and 73.4%, respectively); however, these differences were not statistically significant. Our ≥18 years old sample was more likely to meet physical activity recommendations. Only 29% did not meet the recommendations (ie, ≥150 minutes per week of moderate to vigorous aerobic physical activity<sup>32</sup>), compared to 41.1% in the state (*P* = .003) and 45.1% nationally (*P* <.001).

## Discussion

This study is the first to examine multiple health risk behaviors in a sample of primarily AA and NHOPI AYASCC. KMCWC is the only hospital in Hawai'i that delivers comprehensive care for children with cancer. Its clinic was well suited for our investigation due to the large percentage of AA and NHOPI in Hawai'i.

Our results indicate that our sample of largely AA and NHOPI <18 years AYASCC had significantly lower rates of tobacco

and alcohol use compared to state and national data, regardless of race, and when compared to YRBSS rates reported for AA and Pacific Islander high school students (data combined across four years).<sup>20</sup> The ≥18 year old sample was less likely to have smoked in their entire life or be a current smoker than both state and national samples (*P*-values <.001). More Hawai'i AYASCC met national guidelines for physical activity compared to their peers, although many (44% <18 years and 29% ≥18 years) still failed to meet their national age-specific guidelines. A significantly higher proportion of AYASCC ate fewer than 5 fruits/vegetables a day.

Direct comparisons with previously published studies are difficult due to differences in sample sizes, survey methodology, and patient characteristics. However, our results appear consistent with previous CCSS findings with respect to smoking in ethnic minority (Hispanic and Black) adult survivors of childhood cancer.<sup>21</sup> Also, our >18 year old AYASCC sample had much lower smoking rates than similarly aged AYASCC in two large studies- the CCSS and COG.<sup>10,11</sup> Reported drinking rates were significantly lower among both of our AYASCC samples compared to BRFSS data from national samples and previous AYASCC samples.<sup>10,21</sup> The levels of inactivity in the Hawai'i AYASCC were comparable to several previous findings for AYASCC,<sup>7,11</sup> but not as high as the 70-80% rates of inactivity reported in other studies.<sup>33,34</sup> Thus, for several behavioral risk factors, including tobacco, alcohol, and physical activity, the risks in our largely AA and NHOPI sample of AYASCC were lower than risks for their similarly aged non-cancer peers in Hawai'i, across the United States, and the largely white AYASCC samples in previously published reports.

It should be emphasized that an overwhelming majority of both our <18 year old and ≥18 year old AYASCC did not meet national guidelines for eating fruit and vegetables five times a day. The 96% non-compliance rate seen in our <18 year olds

was higher than previously reported (75.6%) for AYASCC pre-adolescents,<sup>35</sup> and was significantly higher than the state or national rates for this age group. Insufficient fruit/vegetable intake for our  $\geq 18$  year old AYASCC was no different from state and national averages, and was similar to the amounts (76% and 79%) in previous evaluations of the dietary practices of AYASCC.<sup>18,36</sup>

There are numerous influences that shape adolescents' food choices, particularly for fruits and vegetables, including genetic, social, cultural, media/marketing, and physical environmental factors.<sup>37,38</sup> It is difficult to pinpoint why so many of our adolescent AYASCC in Hawai'i failed to meet national recommendations with regard to diet, particularly in light of their levels of physical activity, since both healthy and unhealthy behaviors tend to cluster together.<sup>39,40</sup> It could possibly reflect residual influences resulting from a required avoidance of some fruits and vegetables during cancer treatments undergone during developmental phases (6-10 years of age) when taste preferences are formed or solidified.<sup>41,42</sup> Although our data is cross-sectional, since AYASCC  $\geq 18$  years had a higher consumption of fruits/vegetables, perhaps it is because AYASCC eventually increase their consumption as they grow up, and their intake then becomes more comparable to the US average for adults. The instruments used to measure fruit and vegetable intake in the YRBSS / BRFSS collected the number of occasions or times per day a fruit or vegetable was eaten (ie, serving sizes were not described or reported), and so this method may underestimate the intake of some foods. For example, a large green salad could represent three or more servings of vegetables, but using the YRBSS method it would only count as one occasion or time per day when a vegetable was eaten.

### Study Limitations

Although it was comparable to some other studies of childhood cancer survivors, a possible limitation of our study was its 29.8% response rate and the resulting small sample size. One survey of young adult cancer survivors recruited from cancer organizations (aged 18-40 years) had a lower response rate of 14.7%,<sup>43</sup> while other surveys of adolescent and adult cancer survivors identified through medical records and registries had similar response rates of 33%-38%.<sup>44-46</sup> Another potential limitation is social desirability, or a tendency to answer questions in ways subjects thought were more acceptable. The study's sample size precluded analyses based on time from diagnosis, cancer type, or gender and race comparisons. Thus, we aggregated data from the diverse race/ethnic groups that comprise our AA and NHOPI survivors, which is unfortunate since research with healthy teens has found differences in the prevalence of health behaviors across these ethnicities/races.<sup>20,47,48</sup> For example, our results for a combined sample of AA and NHOPI cancer survivors could mask substantial differences in high risk behaviors between populations with very different social and

cultural backgrounds, as was found in national YRBSS data where healthy Pacific Islander teens had significantly higher rates of smoking and alcohol use, compared to Asian teens.<sup>20</sup> Finally, our sample combined middle school and high school aged survivors, while the YRBSS representative samples differentiate between these two age groups. The YRBSS is also only conducted in public schools across the United States, and we did not ask our survivors if they went to public or private school. However, the majority of our AYASCC were from families that used state or federal-funded insurance; thus, our respondents may have been more likely to have attended public schools. These factors including the differences in our survey methodologies, especially the telephone survey we used for  $< 18$  year old survivors, affect the generalizability of our findings, particularly with respect to the health behaviors of specific race/ethnic subgroups within AA and NHOPI adolescent/young adult survivors of childhood cancer.

### Implications

These results reveal a need for AYASCC survivors to have a better appreciation of the late effects of their cancer therapies, including an increased risk for chronic diseases. Intake of fruits and vegetables and physical activity are behaviors that have been identified as opportunities for improvement in AYASCC.<sup>49</sup> Previous research by others indicates that AYASCC with a higher level of readiness to make a change in physical activity were more motivated and had fewer barriers to increasing their physical activity.<sup>18,33</sup> These results and those from the published literature raise several important questions that could be addressed in future research projects. Differences in health behavioral risk factors based on medical issues (ie, time since cancer diagnosis), cancer diagnosis, race/ethnicity, level of motivation to make a change in a risky behavior, and psychosocial factors could be pursued in future investigations of AYASCC. Also, research might be proposed to test the design and evaluation of a clinical management system (linked to or delivered via an electronic medical records program) that would assess AYASCC's motivation to change a health behavior and also facilitate appropriate physician-based advice to decrease lifestyle risks tailored to that level of motivation.

### Conflict of Interest

None of the authors identify a conflict of interest.

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