

Sociodemographic Disparities in Quality of Life for Survivors of Adolescent and Young Adult Cancers in the Behavioral Risk Factor Surveillance System

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Purpose: Survivors of cancer diagnosed during adolescence and young adulthood (AYA; aged 15–39) may experience quality of life (QOL) limitations; however, little is known about QOL for AYA survivors who are now middle-aged or among racial/ethnic minority survivors. We evaluated QOL outcomes for AYA cancer survivors relative to a non-cancer comparison group by gender, race/ethnicity, and current age.

Methods: Using the 2009 Behavioral Risk Factor Surveillance System (BRFSS) data, we identified 8375 individuals diagnosed with cancer while aged 15–39 years old and 334,759 controls. Participants were currently ≥ 20 years of age. QOL was measured using four items from the Center for Disease Control's Healthy Days Measure (general health, number of days of poor physical and mental health, and activity limitation days). Multivariable regressions compared these measures for survivors and controls by gender, race/ethnicity, and age, and among survivors to determine cancer-related factors associated with poor QOL.

Results: Survivors were more likely to report fair/poor general health than controls (relative risk = 1.92; 95% confidence interval: 1.77–2.10; $p < 0.001$). QOL limitations existed by gender and race/ethnicity for survivors. Approximately 30% of survivors currently in their 40s, 50s, and early 60s were in poor health, compared to less than 20% of same-aged controls (both $p < 0.001$). Of survivors with two or more cancers, 41.0% reported poor health, compared to 26.2% with one cancer ($p < 0.001$).

Conclusion: AYA cancer survivors have worse QOL compared to the general population and these limitations persist across gender, race/ethnicity, and age. Targeted interventions are essential for improving AYA cancer survivors' health status.

Keywords: quality of life, survivor, BRFSS, population

NEARLY 70,000 ADOLESCENTS AND YOUNG ADULTS (AYAs) aged 15–39 years old are diagnosed with cancer each year in the United States.¹ AYAs face an eight-fold higher risk of being diagnosed with cancer than children under the age of 15,² yet survivorship research has typically focused on younger or older cancer patients to the exclusion of AYAs.³ Adolescence and young adulthood are times of complex physical and psychosocial development, coupled with substantial lifestyle changes. Adolescents often leave home for school, begin working, and become more independent from their parents, while young adults tend to be focused on completing their education, pursuing employment, getting married, and having children. As such, a cancer diagnosis during this period may

cause significant disruption to AYAs' physical, social, and psychological development, potentially leading to diminished quality of life (QOL).^{2,4,5}

Unlike improvements seen in younger and older age groups, survival rates for AYAs diagnosed with cancer have changed little in nearly 30 years.⁶ AYA cancer patients face many unique healthcare challenges. AYAs—in particular males—often forego preventative care and young adults are often uninsured, which can prohibit the early detection and treatment of cancer and hinder utilization of follow-up care.^{2,7} In addition, there are few recommendations for cancer screening in younger populations, and providers may be dismissive of symptoms as cancer is uncommon in this age range.² Access to

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age-appropriate support services during treatment and follow-up, including mental health services or financial assistance, may be inadequate. AYA patients report a lack of support for physical and psychosocial service needs during treatment, such as pain management or physical therapy.⁸ Moreover, the greatest information and service needs are reported by AYA patients who have completed therapy, rather than those who are currently undergoing treatment, demonstrating the ongoing impact of cancer long after diagnosis.⁸

To date, the majority of studies specific to AYA cancer survivors' QOL outcomes have been restricted to samples of specific cancer diagnoses, drawn from a limited number of state cancer registries or clinics, or conducted without comparison groups.^{9–13} In addition, while the national Childhood Cancer Survivor Study has contributed information about adolescents diagnosed with cancer at ages 15–20,¹⁴ survivors who were diagnosed at ages 21–39 have been understudied. Population-based analyses report that AYA cancer survivors' mental and physical health is poorer than respondents without a cancer history,¹⁵ but little is known about QOL disparities among gender, age, and racial/ethnic subgroups. As a result, representative studies are needed to capture unique QOL issues that may emerge for older survivors of AYA cancers and that determine whether racial or ethnic minority AYA survivors are at particular risk for poor QOL outcomes.

Here we report on QOL outcomes for survivors of AYA cancer diagnosed while aged 15–39 from the 2009 Behavioral Risk Factor Surveillance System (BRFSS) dataset compared to unaffected controls. While BRFSS is conducted among adults ≥ 18 , participants are asked their age of first cancer diagnosis, allowing us to investigate survivors diagnosed in adolescence. Using four measures of health status—general health and the number of poor physical health, poor mental health, and activity limitation days per month—we provide a population-based perspective of the health burden for AYA cancer survivors. BRFSS data provide a unique resource for capturing QOL for a wide age range of AYA survivors, including survivors currently in adolescence and young adulthood, as well as survivors of AYA cancer who are now in their 40s, 50s, and 60s. Our goal was to describe the QOL limitations of both older and younger survivors of AYA cancer and differences by gender and race/ethnicity. We also investigate the impact of understudied cancer factors, such as multiple cancer diagnoses, on AYAs' QOL.

Methods

The BRFSS is an annual, nationally-representative computer-assisted survey implemented in the United States (U.S.), the District of Columbia, and certain U.S. territories (Puerto Rico, Guam, and the Virgin Islands; www.cdc.gov/brfss). It uses random-digit telephone dialing methods to sample both English and Spanish-speaking non-institutionalized adults ≥ 18 years old. The 2009 BRFSS response rate was 53%.¹⁶

Participants

A total of 432,607 individuals participated in the 2009 BRFSS. We limited our eligible sample to U.S. participants, including Washington D.C., ($N=424,592$) due to differences in healthcare in the U.S. territories. Individuals with cancer were identified from the question, “*Have you ever been told by a doctor, nurse, or other health professional that you had*

cancer?” The test–retest reliability for this question is high ($k=0.91$).¹⁷ Participants indicating a cancer history were asked the age at diagnosis for their first primary cancer. We excluded those with a cancer diagnosed at ages <15 or ≥ 40 ($n=48,134$). Additional exclusions included: missing cancer information ($n=24,974$), current age less than 20 ($n=6231$), and diagnosis of non-melanomatous skin cancer ($n=2119$). Based on our inclusion criteria, there were 8375 participants with cancer diagnosed at ages 15–39 who were ≥ 5 years from diagnosis and $N=334,759$ controls with no cancer history.

Measures

Quality of life outcomes. The BRFSS includes four items, known as the Healthy Days Measure, that investigate QOL.¹⁸ Perceived sense of well-being is assessed in four areas: (1) self-rated general health (excellent/very good/good/fair/poor); (2) number of recent days (within the past 30 days) when physical health was not good; (3) number of recent days when mental health was not good; and (4) number of recent activity limitation days because of poor physical/mental health.¹⁹ These items have been validated in non-institutionalized U.S. samples¹⁸ and used in earlier cancer survivor studies.²⁰ Due to skewed data, we dichotomized self-rated health as excellent/very good/good vs. fair/poor. Similar to earlier Healthy Days Measure reports,¹⁹ we dichotomized at ≥ 15 days of physical, mental, or activity limitation per month. We also examined the Healthy Days Measures as counts; however, as these estimates did not differ substantially from the dichotomized estimates, we report our analyses based on the dichotomized Healthy Days Measures.

Demographics and cancer measures. Demographics included gender (male or female), current age (20–29, 30–39, 40–64, or ≥ 65 years) and race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic/Latino, non-Hispanic Other race (includes Asian/Pacific Islander and American Indian/Alaska Native), or non-Hispanic Multiracial), and other variables (Table 1). Cancer factors included diagnosis groups (breast, thyroid, melanoma, colorectal, Hodgkin lymphoma, non-Hodgkin lymphoma, testicular, bone, brain, leukemia, cervical, ovarian, endometrial, or other), number of cancer diagnoses at any age (1, 2, or 3), age at first primary cancer diagnosis (15–29 or 30–39), and years since initial cancer diagnosis (5–10, 11–15, 16–25, 26–30, 31–35, 36–40, or >40). As participants were only asked the diagnosis type of their original cancer, we were unable to exclude non-melanomatous skin cancers for second or tertiary cancers.

Statistical analysis

Descriptive statistics of raw counts and BRFSS weight-adjusted proportions were calculated for demographic variables categorized by current age (20–39 or ≥ 40) and among those with an AYA cancer history. Within the AYA survivor group, raw counts and adjusted proportions were calculated for the original cancer diagnosis, number of cancer diagnoses, age at diagnosis (15–29 or 30–39), and years since diagnosis.

Logistic regressions were used to examine associations of self-rated health and Healthy Days for AYA cancer survivors versus controls. We also investigated the total number of days for each of the Healthy Days Measures as a count using

negative binomial regression models. Analyses were refined by analyzing the effects of gender and race/ethnicity between the two groups, adjusting for gender, race/ethnicity, and current age as relevant. Logistic regressions were used within the AYA cancer group to determine associations between cancer type, number of cancer diagnoses (1 or ≥ 2), age at diagnosis (15–19, 20–24, 25–29, 30–34, or 35–39), and years since diagnosis (5–10, 11–20, 21–30, or ≥ 31) on the four outcomes, adjusted for gender, race/ethnicity, and years since diagnosis. Results are presented as a BRFSS weight-adjusted percentage along with its 95% confidence interval (CI).

Data were analyzed using appropriate procedures in SAS 9.3 and SUDAAN 11.0, taking into account the complex sampling design (SAS Institute, Cary, NC; SUDAAN, RTI, Research Triangle Park, NC). Adjusted proportions in the logistic regression procedure were calculated using the average marginal prediction (model-adjusted risk).²¹ The 95% confidence interval and corresponding *p*-value were calculated using the standard error of the adjusted proportions from the average marginal prediction procedure.

Results

Table 1 shows participant characteristics by current age for the cases and the controls. The survivor sample for both age groups tended to be female and non-Hispanic White more

often than the controls. In male AYA survivors aged 20–39 years at the time of survey, non-Hodgkin lymphoma (20.3%), testicular cancer (19.0%), and Hodgkin lymphoma (12.9%) were the most common diagnoses, compared to melanoma (26.8%) and testicular cancer (13.5%) in older males (Table 2). Female survivors currently aged 20–39 years tended to have a history of cervical cancer (52.5%), ovarian cancer (9.1%), or melanoma (8.7%), in contrast with a history of cervical (34.1%) and breast (16.0%) cancers among women currently aged 40 and older.

Survivors' quality of life is impaired more than controls

For the full survivor sample, 17.2%–28.3% met the criteria for poor QOL on one of the four measures, compared to 9.1%–14.7% of controls (Table 3). In particular, survivors had a two-fold higher risk of having fair/poor health (28.3% survivors vs. 14.7% controls; relative risk [RR] = 1.92; 95% CI: 1.77–2.10; *p* < 0.001; not shown in table). For the full sample, we modeled the number of days per month in negative binomial regression models (not shown in table) and found that survivors' number of poor physical (incidence rate ratio [IRR] = 2.06; 95% CI: 1.91–2.22; *p* < 0.001), poor mental (IRR = 1.66; 95% CI: 1.55–1.79; *p* < 0.001), and activity limitation (IRR = 1.82; 95% CI: 1.67–1.98; *p* < 0.001) days per month exceeded the control group.

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF SURVIVORS OF AYA CANCERS AND CONTROLS BY CURRENT AGE

	Currently ages 20–39				Currently ages ≥ 40			
	AYA cancer survivors		Controls		AYA cancer survivors		Controls	
	n	% ^a	n	% ^a	n	% ^a	n	% ^a
Gender								
Male	242	23.9	24,901	50.2	1082	22.5	102,767	48.0
Female	1344	76.1	40,671	49.8	5707	77.5	166,420	52.0
Current age								
20–29	350	28.5	21,254	44.6	—	—	—	—
30–39	1236	71.5	44,318	55.4	—	—	—	—
40–64	—	—	—	—	4935	81.1	176,663	76.2
≥ 65	—	—	—	—	1854	18.9	92,524	23.8
Race/ethnicity								
Non-Hispanic White	1204	72.1	46,094	61.8	5798	82.1	219,311	73.5
Non-Hispanic Black	103	7.6	6342	11.1	322	7.1	20,838	10.0
Hispanic/Latino	131	11.0	7672	18.8	242	5.4	13,047	10.6
Non-Hispanic Other	84	5.5	3665	6.4	203	2.9	9128	4.5
Non-Hispanic Multiracial	57	3.8	1399	1.8	182	2.4	4138	1.4
Education								
High school education	530	36.9	20,900	34.5	2571	34.4	107,160	38.1
Some college/vocational	546	31.8	19,072	29.1	2123	30.3	71,571	25.4
College graduate	510	31.3	25,541	36.3	2086	35.3	90,026	36.4
Health insurance								
Yes	1284	79.9	52,840	76.5	6087	89.1	244,421	88.8
No	301	20.1	12,573	23.5	694	10.9	24,328	11.2
Employment status								
Employed	947	59.7	46,141	67.3	3092	49.0	133,312	56.5
Out of work	179	10.4	6062	11.6	426	9.4	14,111	6.9
Not in labor force	283	20.4	11,224	18.1	2158	27.4	101,502	29.7
Unable to work	174	9.2	1996	2.7	1105	13.9	19,650	6.7

^aWeighted for BRFSS sampling.

AYA, adolescent and young adult; BRFSS, Behavioral Risk Factor Surveillance System.

TABLE 2. CANCER DIAGNOSES AND CANCER FACTORS OF SURVIVORS OF AYA CANCERS BY GENDER AND CURRENT AGE

	Male				Female			
	Ages 20–39		Ages ≥40		Ages 20–39		Ages ≥40	
	n	% ^a	n	% ^a	n	% ^a	n	% ^a
<i>Original diagnosis^b</i>								
Breast cancer	1	2.4	5	0.4	37	3.7	915	16.0
Thyroid cancer	4	1.2	54	4.4	41	3.9	274	4.9
Melanoma	21	8.8	298	26.8	83	8.7	503	8.4
Colorectal cancer	3	1.1	68	6.4	7	0.6	145	2.5
Hodgkin lymphoma	11	12.9	50	5.7	22	4.2	93	1.9
Non-Hodgkin lymphoma	8	20.3	31	3.3	10	0.9	35	1.1
Testicular cancer	28	19.0	128	13.5	—	—	—	—
Bone cancer	6	3.8	10	0.4	3	1.3	22	0.3
Brain cancer	5	1.2	21	1.9	6	1.1	23	0.5
Leukemia	4	3.2	28	2.5	9	1.2	38	0.8
Cervical cancer	—	—	—	—	443	52.5	1902	34.1
Ovarian cancer	—	—	—	—	80	9.1	439	8.4
Endometrial cancer	—	—	—	—	42	5.2	583	9.1
Other ^c	32	26.2	362	34.7	62	7.7	624	11.9
<i>Number of cancer diagnoses^b</i>								
1	117	97	809	78.3	756	90.1	4458	81.1
2	4	2	188	16.5	70	8.8	906	14.6
3	2	0.9	58	5.2	19	1.1	232	4.3
<i>Age at diagnosis, years^b</i>								
15–29	101	81.6	356	33.7	739	89.6	2442	43.4
30–39	22	18.4	699	66.3	106	10.4	3154	56.6
<i>Years since diagnosis^b</i>								
5–10	71	67.9	118	14.9	441	54.9	378	10.7
11–15	27	21.5	125	16.2	249	28.7	481	12.0
16–25	25	10.6	272	28.6	155	16.4	1567	30.6
26–30	—	—	133	13.8	—	—	908	15.5
31–35	—	—	116	9.3	—	—	793	10.9
36–40	—	—	113	7.3	—	—	601	8.6
>40	—	—	178	9.9	—	—	868	11.6

^aWeighted for BRFSS sampling.^bEstimates may be unstable due to small cell sizes (<50 participants) in certain subgroups.^cOther cancers: cancers reported by <1% of the sample, including stomach, bladder, pancreatic, esophageal, and lung, as well as cancers only coded as “Other” by BRFSS.

AYA, adolescent and young adult; BRFSS, Behavioral Risk Factor Surveillance System.

QOL deficits among AYA cancer survivors persisted by gender (Table 3). Over 30% of female survivors had fair/poor general health compared to 15.3% of female controls (RR = 2.05; 95% CI: 1.91–2.20; $p < 0.001$; RRs not shown in table). For male survivors, this difference was slightly attenuated, although still present (25.2% of survivors vs. 14.1% controls reporting fair/poor health; RR = 1.78; 95% CI: 1.49–2.13; $p < 0.001$). Similarly, the proportions of female and male survivors reporting ≥15 poor physical health days, ≥15 poor mental health days, and ≥15 activity limitation days were consistently 4%–12% higher than the controls ($p < 0.05$ for all comparisons).

Survivors of all racial/ethnic groups had poorer QOL than their respective controls. For poor/fair health, survivors reporting race/ethnicity as non-Hispanic White (25.0% vs. 11.5%; $p < 0.001$), non-Hispanic Black (29.3% vs. 20.8%; $p = 0.03$), Hispanic/Latino (40.5% vs. 27.7%; $p = 0.004$), Other (46.6% vs. 14.2%, $p < 0.001$), and Multiracial (42.0% vs. 20.6%; $p < 0.001$) were at higher risk compared to controls. All racial/ethnic groups reported ≥15 poor physical

health days, ≥15 poor mental health days, and ≥15 activity limitation days in greater numbers when compared to controls.

Poor general health and physical health exist across age for survivors

Across all age groups, survivors were more likely to report poor health status than controls (Fig. 1). The proportion reporting fair/poor health ranged from a low of 26.7% for survivors aged 30–39 versus 8.7% of the controls ($p < 0.001$) to a high of 36.4% of survivors aged ≥65 versus 26.2% ($p < 0.001$) of the controls. Approximately 30% of survivors currently in their 40s, 50s, and early 60s were in poor general health, compared to only 13%–20% of controls (both $p < 0.001$). Survivors also had more poor physical health days, with a high of 22.6% of survivors aged 50–64 reporting ≥15 days of poor physical health per month compared to 12.9% of the controls ($p < 0.001$). Activity limitation days peaked with the 50–64 year-old age group,

TABLE 3. ADJUSTED PROPORTIONS AND 95% CONFIDENCE INTERVALS OF SURVIVORS OF AYA CANCERS AND CONTROLS REPORTING POOR QUALITY OF LIFE BY GENDER AND RACE^a

	<i>Fair/poor general health</i>			<i>≥ 15 days of poor physical health per month</i>			<i>≥ 15 days of poor mental health per month</i>			<i>≥ 15 days of activity limitations per month</i>		
	%	95% CI	p-Value	%	95% CI	p-Value	%	95% CI	p-Value	%	95% CI	p-Value
Full sample												
Controls	14.7	14.5–15.0	<0.001	9.1	8.9–9.3	<0.001	10.0	9.8–10.2	<0.001	11.8	11.5–12.2	<0.001
Survivors	28.3	25.9–30.8		20.6	18.3–22.9		17.2	15.2–19.3	<0.001	21.8	19.2–24.3	
Gender												
Female												
Controls	15.3	14.9–15.6	<0.001	10.0	9.7–10.2	<0.001	11.4	11.1–11.7	<0.001	11.6	11.2–11.9	<0.001
Survivors	31.3	29.2–33.3		22.0	20.2–23.7		21.6	19.8–23.5		24.0	21.5–26.5	
Male												
Controls	14.1	13.8–14.5	<0.001	8.2	7.9–8.5	<0.001	8.5	8.2–8.9	0.03	12.2	11.7–12.8	0.005
Survivors	25.2	20.7–29.7		19.1	14.8–23.4		12.6	9.0–16.3		18.8	13.9–23.8	
Race/ethnicity												
Non-Hispanic White												
Controls	11.5	11.3–11.7	<0.001	8.2	8.1–8.4	<0.001	9.5	9.2–9.7	<0.001	10.7	10.4–11.0	<0.001
Survivors	25.0	23.2–26.8		18.5	17.0–20.1		17.3	15.7–18.9		20.4	18.3–22.5	
Non-Hispanic Black												
Controls	20.8	19.9–21.7	0.03	10.8	10.1–11.5	0.03	12.0	11.2–12.8	0.01	15.4	14.3–16.5	<0.001
Survivors	29.3	21.7–37.0		17.3	11.3–23.3		22.1	13.1–31.1		33.4	19.8–47.0	
Hispanic/Latino												
Controls	27.7	26.5–28.9	0.004	12.6	11.7–13.5	<0.001	11.1	10.3–11.9	0.02	14.4	13.0–15.8	0.002
Survivors	40.5	31.5–49.5		26.0	18.0–34.1		18.5	11.9–25.1		26.7	17.6–35.8	
Non-Hispanic Other												
Controls	14.2	13.1–15.4	<0.001	9.1	8.1–10.1	<0.001	8.6	7.6–9.5	0.002	12.4	10.8–13.9	<0.001
Survivors	46.6	31.7–61.6		36.5	20.9–52.2		19.6	10.8–28.3		31.7	18.3–45.2	
Non-Hispanic Multiracial												
Controls	20.6	18.4–22.9	<0.001	13.4	11.6–15.2	<0.001	15.5	13.0–17.9	0.04	16.0	12.9–19.1	0.03
Survivors	42.0	28.4–55.7		32.6	19.3–45.9		28.0	15.3–40.6		32.6	16.3–48.8	

^aModels adjusted for gender, race/ethnicity, and current age. AYA, adolescent and young adult; CI, confidence interval.

with 29.4% of survivors reporting ≥ 15 days of activity limitation versus 17.0% of the controls ($p < 0.001$). By age ≥ 65 , the difference between survivors and controls was not statistically significant.

Younger survivors had the poorest mental health. Fifteen or more days of poor mental health peaked at 24.1% of survivors aged 20–29, compared to 10.8% of the controls ($p < 0.001$). By age ≥ 65 , only 10.4% of survivors and 5.9% of the controls reported poor mental health ($p < 0.001$).

Cancer-related factors impact quality of life

Female survivors with a history of breast, cervical, ovarian, colorectal, or “other” cancers had an elevated risk of QOL limitations for all four outcomes compared to the unaffected sample (Table 4). Particularly apparent were problems with general health, for which 23.8% of breast, 31.3% of cervical, 42.0% of ovarian, and 44.7% of colorectal female survivors compared to 15.3% of female controls were in poor/fair health ($p < 0.001$). For males, only “other” cancers were more likely to report poor health across all domains.

Our final set of models investigated QOL among survivor subgroups (Table 5). Survivors reporting two or more cancer diagnoses had poorer health on all four measures of QOL than those reporting one cancer diagnosis. The most appreciable difference was that 41.0% of survivors with two or more diagnoses reported fair/poor health compared to 26.2%

of those with one diagnosis ($p < 0.001$). For age at diagnosis, only mental health differed, with 14.6% survivors diagnosed at ages 35–39 having ≥ 15 days of poor mental health compared to 25.0% of survivors diagnosed at ages 15–19 ($p = 0.006$). Longer time since diagnosis was associated with poorer QOL, with 35.4% survivors ≥ 30 years from diagnosis reporting fair/poor health versus 27.6% of those only 5–10 years from diagnosis ($p = 0.05$). Survivors more than 30 years from diagnosis had ≥ 15 days of poor physical health most often (27.6% vs. 20.2% 5–10 years; $p = 0.05$).

Discussion

Our findings suggest that survivors of cancer diagnosed during adolescence and young adulthood have pervasive QOL issues across their lifespans and poor health status. Our results are similar to an earlier BRFSS study that found lower QOL among respondents aged 20 to 64 years who reported being limited by cancer.²⁰ Age-related deficits were high for survivors with regard to general health, physical health, and activity limitations. For survivors of cancers diagnosed in the AYA age period who are now in their 40s, 50s, and early 60s, approximately 30% reported poor or fair health compared to 20% or less of those without a cancer history. We found that AYA survivors reporting more than one cancer diagnosis had substantially poorer QOL, notable given that second cancers are a

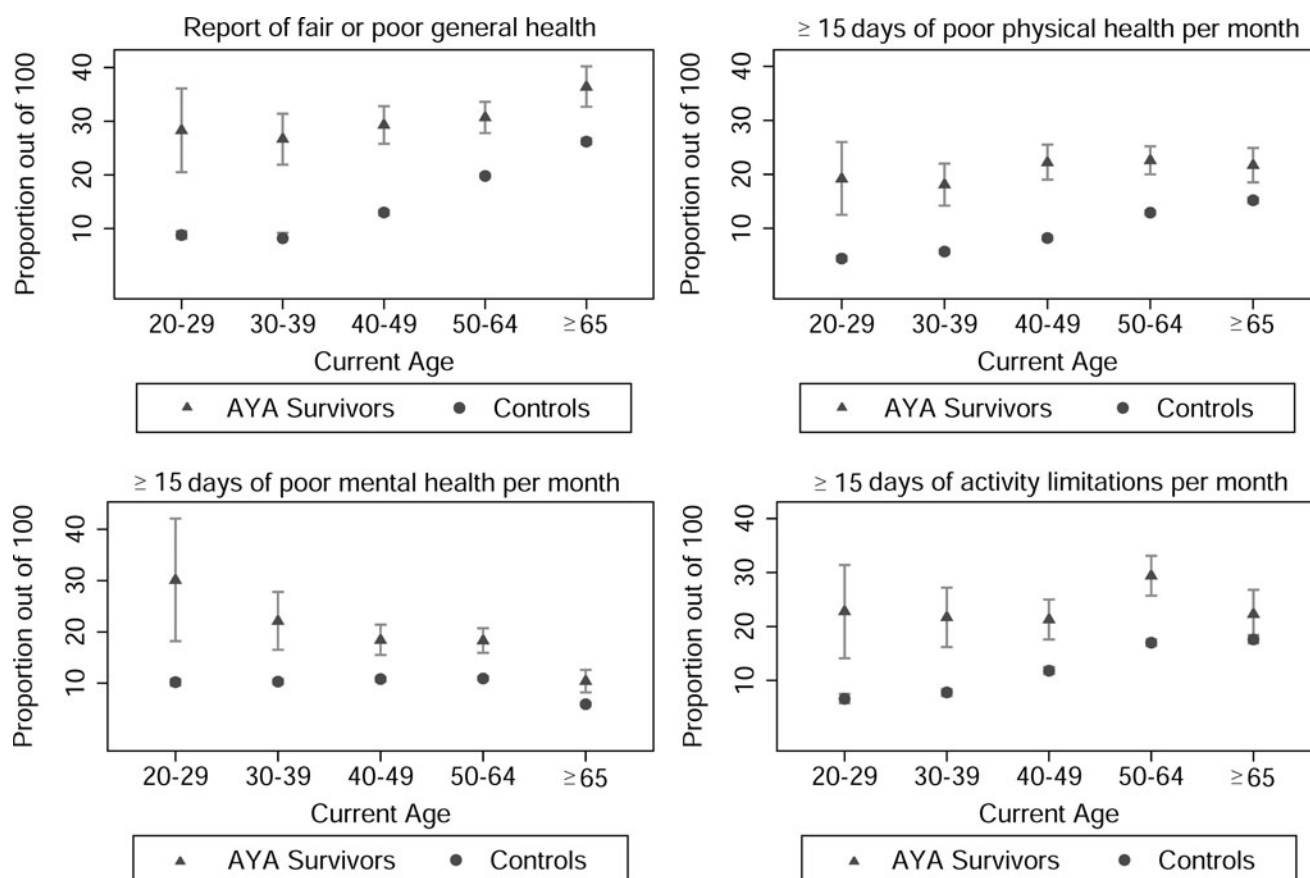


FIG. 1. Adjusted proportions and 95% confidence intervals of survivors of AYA cancers and controls reporting poor quality of life by current age. *Note:* Models adjusted for gender and race/ethnicity. All comparisons significant at $p=0.05$, except ages ≥ 65 in the 15 or more days of activity limitations per month ($p=0.06$). AYA, adolescent and young adult.

concern due to the risks associated with radiotherapy and chemotherapy.²²

Using BRFSS data improves on earlier studies of survivors of AYA cancer that have often lacked comparison groups and/or national samples. We found that survivors experienced fair to poor QOL with a frequency twice that of the general population, and had more impaired mental, physical, and activity days. The proportion of AYAs reporting poor QOL was similar to the proportion reported by other young populations with chronic conditions, such as arthritis.²³

Almost half of female survivors of certain cancers, such as ovarian (42.0%) or colorectal, (44.7%) had fair/poor health. Therapies are often intensive for these cancers and are associated with long-term issues such as infertility²⁴ and functional bowel problems²⁵ that may cause daily struggles. The BRFSS requires participants to select predetermined cancer categories, which do not include certain common AYA cancers (e.g., soft tissue sarcomas).⁶ The small sample size (<1% of the sample) for cancers such as stomach, bladder, esophageal, and lung cancers, as well as common AYA cancers not listed specifically in the BRFSS, resulted in 26.2% of males currently aged 20–39 and 34.7% of males currently aged ≥ 40 grouped in the “other” diagnosis category. For males, the “other” diagnosis category was the only one that had significantly poorer QOL than controls. The BRFSS and other national health surveys that collect cancer information should be

encouraged to capture more specific diagnostic information so that cancers common in younger age groups, such as sarcomas, are not missed.

We identified potential developmental differences related to AYA cancer survivors' QOL. Survivors aged 35–39 at diagnosis, the upper range of the AYA cancer age spectrum, tended to have fewer days of poor mental health than the youngest AYAs (aged 15–19 at diagnosis). For these younger patients at diagnosis—a group that falls “in between” the pediatric and adult oncology settings—additional supportive care services are likely needed to manage mental health stressors. Many adolescents are treated at adult centers²⁶ where adolescent-focused social workers, psychologists, and therapists may be lacking. The opportunities to detect psychological issues for adolescent cancer patients require age-sensitive services to identify and address QOL needs.

Not surprisingly, survivors with multiple cancers and who are decades from their original diagnosis had some of the poorest health. Over one-third of survivors who are 30 or more years from diagnosis reported fair/poor health. Survivors of AYA cancers are likely to follow a trajectory similar to that of childhood cancer survivors, amongst whom over 70% at ≥ 30 years post-diagnosis have at least one chronic health condition and 42% have severe, disabling, or life-threatening conditions (such as second cancers) or have died.²⁷ While the information on chronic disease in the BRFSS is limited, we anticipate conducting future reports to

TABLE 4. ADJUSTED PROPORTIONS AND 95% CONFIDENCE INTERVALS OF SURVIVORS OF AYA CANCERS BY DIAGNOSIS AND CONTROLS REPORTING POOR QUALITY OF LIFE^a

	<i>Fair/poor general health</i>			<i>≥15 days of poor physical health per month</i>			<i>≥15 days of poor mental health per month</i>			<i>≥15 days of activity limitations per month</i>		
	%	95% CI	p-Value	%	95% CI	p-Value	%	95% CI	p-Value	%	95% CI	p-Value
<i>Female</i>												
Controls (ref)	15.3	15.0–15.6		9.9	9.7–10.2		11.3	11.0–11.6		11.5	11.2–11.9	
Breast	23.8	18.9–28.6	<0.001	16.5	12.8–20.1	<0.001	16.9	13.0–20.8	0.002	17.8	12.9–22.7	0.007
Cervical	31.3	27.7–34.9	<0.001	21.6	18.7–24.6	<0.001	24.5	21.3–27.8	<0.001	24.2	20.4–28.0	<0.001
Ovarian	42.0	33.7–50.3	<0.001	32.8	24.9–40.6	<0.001	25.9	19.1–32.7	<0.001	26.4	18.4–34.3	<0.001
Thyroid	21.1	14.5–27.8	0.10	11.4	6.1–16.7	0.68	11.2	6.2–16.1	0.80	7.9	3.8–12.0	0.29
Melanoma	16.6	12.5–20.7	0.65	13.2	9.1–17.2	0.16	12.1	7.9–16.3	0.74	14.2	8.8–19.6	0.45
Colorectal	44.7	29.4–60.1	<0.001	33.8	18.3–49.4	<0.001	25.8	14.1–37.5	0.001	27.4	13.7–41.1	0.003
Hodgkin	26.5	14.0–39.0	0.06	19.9	8.6–31.3	0.05	16.8	6.2–27.5	0.37	15.8	3.6–27.9	0.58
Other	35.4	30.6–40.1	<0.001	24.6	20.6–28.6	<0.001	21.8	17.4–26.2	<0.001	26.8	21.4–32.1	<0.001
<i>Male</i>												
Controls (ref)	13.6	13.2–14.0		7.8	7.5–8.1		8.5	8.1–8.8		11.4	10.9–11.9	
Non-Hodgkin	17.2	0.3–34.2	0.71	6.1	–3.2–15.4	0.76	29.4	–6.5–65.4	0.11	9.1	–5.6–23.8	0.77
Testicular	9.7	3.4–15.9	0.47	11.9	4.2–19.6	0.35	3.2	0.8–5.5	0.03	9.9	1.7–18.2	0.76
Thyroid	22.2	3.1–41.2	0.43	15.5	–5.3–36.3	0.48	16.8	–8.4–42.0	0.53	3.2	–0.6–7.0	0.09
Melanoma	14.7	9.0–20.3	0.74	9.5	4.4–14.7	0.61	10.8	4.3–17.3	0.58	5.2	2.2–8.2	0.02
Colorectal	14.7	3.6–25.8	0.78	10.3	1.8–18.8	0.64	10.4	0.9–19.9	0.72	17.4	5.1–29.8	0.40
Hodgkin	27.1	8.7–45.5	0.11	15.1	–0.3–30.5	0.35	8.1	–1.0–17.2	0.80	19.3	–4.9–43.4	0.57
Other	28.5	21.7–35.2	<0.001	21.6	15.4–27.8	<0.001	18.1	11.7–24.4	<0.001	25.2	16.9–33.4	<0.001

^aModels adjusted for age, gender, and race/ethnicity.
ref, reference.

expand on the relationship between health status and disease in this population of survivors of AYA cancer.

Differences in perceived health status and QOL in AYA cancer survivors with respect to race/ethnicity are not well defined in the literature. In our study, among all racial/ethnic groups (non-Hispanic White, non-Hispanic Black, Hispanic/Latino, Other, and Multiracial) survivors reported fair to poor health, ≥15 poor physical health days, ≥15 poor mental

health days, and ≥15 activity limitation days in greater numbers when compared to their respective controls. In the AYA Hope Study, non-White AYA cancer survivors reported a greater number of unmet information and service needs about their cancer, including financial concerns for accessing medical care.⁸ In particular, we found that Hispanic/Latino, Other, and Multiracial survivors had the poorest general health. Future studies are needed to develop

TABLE 5. ADJUSTED PROPORTIONS AND 95% CONFIDENCE INTERVALS OF AYA SURVIVORS REPORTING POOR QUALITY OF LIFE BY CANCER-RELATED FACTORS^a

	<i>Fair/poor general health</i>			<i>≥15 days of poor physical health per month</i>			<i>≥15 days of poor mental health per month</i>			<i>≥15 days of activity limitations per month</i>		
	%	95% CI	p-Value	%	95% CI	p-Value	%	95% CI	p-Value	%	95% CI	p-Value
<i>Number of cancer diagnoses</i>												
1 (ref)	26.2	24.2–28.1		19.8	18.1–21.5		18.4	16.7–20.2		21.8	19.5–24.1	
≥2	41.0	36.1–45.9	<0.001	31.3	26.6–35.9	<0.001	24.9	20.2–29.6	0.01	28.2	23.0–33.4	0.04
<i>Age at diagnosis, years</i>												
15–19 (ref)	28.3	21.3–35.2		19.4	13.6–25.3		25.0	18.1–31.9		21.1	13.9–28.4	
20–24	26.7	22.2–31.2	0.74	21.2	17.0–25.4	0.71	21.3	17.3–25.4	0.52	21.3	16.5–26.1	0.80
25–29	31.8	27.4–36.2	0.57	21.4	17.6–25.2	0.69	22.2	18.3–26.1	0.62	23.4	18.5–28.3	0.71
30–34	29.4	25.5–33.3	0.77	22.8	19.2–26.5	0.52	20.4	16.3–24.5	0.40	27.7	22.7–32.7	0.31
35–39	24.3	20.9–27.8	0.47	19.5	16.3–22.6	0.80	14.6	11.8–17.4	0.006	19.8	15.6–24.1	0.76
<i>Years since diagnosis</i>												
5–10 (ref)	27.6	22.7–32.4		20.2	16.1–24.2	0.76	24.6	19.3–29.9		21.7	16.2–27.1	
11–20	25.2	21.8–28.6	0.58	21.0	17.7–24.3	0.68	19.9	16.8–23.0	0.24	21.3	17.3–25.2	0.79
21–30	28.0	24.7–31.2	0.79	19.9	17.1–22.7	0.78	18.0	15.2–20.7	0.06	22.9	19.2–26.5	0.75
≥31	35.4	31.3–39.6	0.05	27.6	23.6–31.5	0.05	18.8	15.3–22.4	0.16	28.6	23.4–33.9	0.16

^aModels adjusted for gender, race/ethnicity, and years since diagnosis as relevant.

culturally-appropriate strategies to help all AYA cancer survivors manage their long-term health.

BRFSS data has certain limitations. Because the BRFSS somewhat under-represents racial and ethnic minorities,²⁸ our findings may underestimate the QOL deficits for AYA cancer survivors. In addition, for some of our cancer subgroups of interest the number of participants was small, so we caution that certain estimates may be unstable. The BRFSS does not include information about cancer treatment or cancer stage at diagnosis, so we could not explore how these factors influenced our outcomes of interest. In addition, despite the high level of limitations observed across time since diagnosis and current age for AYA cancer survivors, our findings reflect “survivor bias” in that survivors who have died from subsequent late effects are not reflected in these cross-sectional analyses. Finally, BRFSS added cell phones to their sample frame in 2011; therefore, the 2009 sample does not reflect AYAs who only have cell phones.

Conclusion

The ongoing impact of AYA cancer on the lives of surviving adults demonstrates the need for health promotion and wellness programs to help survivors identify and address health problems before QOL deficits become chronic. Our findings add to the growing literature demonstrating the life-long consequences of AYA cancer on patients and survivors. As the number of AYA cancer survivors continues to increase, the public health burden of this population will grow due to the reduced productivity and increased healthcare needs of these survivors. We found that QOL deficits persist across age for survivors of cancer diagnosed in adolescence and young adulthood. In earlier work, we found that many AYA cancer survivors avoid healthcare due to cost concerns,²⁹ meaning that AYA cancer survivors may lack adequate resources for managing their health. Better supportive care during treatment and follow-up, coupled with important tools like survivor care plans that help direct survivors' healthcare and wellness, could help ameliorate some of the long-term sequelae for AYA cancer survivors. Evidence-based interventions are critically needed to improve health, social, and economic outcomes in this cancer survivor population.

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References

1. National Cancer Institute. A snapshot of adolescent and young adult cancers. Bethesda, MD: Department of Health and Human Services, National Institutes of Health, National Cancer Institute; 2012. Accessed December 5, 2011 from: www.cancer.gov/researchandfunding/snapshots/pdf/AYA-Snapshot.pdf
2. Adolescent and Young Adult Oncology Progress Review Group. Closing the gap: research and care imperatives for adolescents and young adults with cancer (NIH Publication No. 06-6067). Bethesda, MD: Department of Health and Human Services, National Institutes of Health, National Cancer Institute, and the LIVESTRONG Young Adult Alliance; August 2006.
3. Tonorezos ES, Oeffinger KC. Research challenges in adolescent and young adult cancer survivor research. *Cancer*. 2011;117(10 Suppl):2295–300.
4. Bellizzi KM, Smith A, Schmidt S, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*. 2012;118(20):5155–62.
5. Parsons HM, Harlan LC, Lynch CF, et al. Impact of cancer on work and education among adolescent and young adult cancer survivors. *J Clin Oncol*. 2012;30(19):2393–400.
6. Bleyer A, O'Leary M, Barr R, Ries L. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000 (NIH Publication No. 06-5767). Bethesda, MD: Department of Health and Human Services, National Institutes of Health, National Cancer Institute; 2006.
7. Nicholson JL, Collins SR, Mahato B, et al. Rite of passage? Why young adults become uninsured and how new policies can help, 2009 update. *Issue Brief (Commonw Fund)*. 2009; 64:1–20.
8. Keegan TH, Lichtensztajn DY, Kato I, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Surviv*. 2012;6(3):239–50.
9. Mattson MR, Demshar RK, Daly BJ. Quality of life of young adult survivors of hematologic malignancies. *Cancer Nurs*. 2013;36(2):E1–7.
10. Yanez B, Garcia SF, Victorson D, Salsman JM. Distress among young adult cancer survivors: a cohort study. *Support Care Cancer*. 2013;21(9):2403–8.
11. Smith AW, Bellizzi KM, Keegan TH, et al. Health-related quality of life of adolescent and young adult patients with cancer in the United States: the Adolescent and Young Adult Health Outcomes and Patient Experience study. *J Clin Oncol*. 2013;31(17):2136–45.
12. 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):305–14.
13. Kent EE, Sender LS, Morris RA, et al. Multilevel socioeconomic effects on quality of life in adolescent and young adult survivors of leukemia and lymphoma. *Qual Life Res*. 2013;22(6):1339–51.
14. Robison LL, Armstrong GT, Boice JD, et al. The Childhood Cancer Survivor Study: a National Cancer Institute-supported resource for outcome and intervention research. *J Clin Oncol*. 2009;27(14):2308–18.
15. Tai E, Buchanan N, Townsend J, et al. Health status of adolescent and young adult cancer survivors. *Cancer*. 2012; 118(19):4884–91.
16. Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System 2009 summary data quality report (version #1, revised February 18, 2011). Accessed November 2, 2011 from: [ftp://ftp.cdc.gov/pub/data/brfss/2009_Summary_Data_Quality_Report.pdf](http://ftp.cdc.gov/pub/data/brfss/2009_Summary_Data_Quality_Report.pdf)
17. Kapp JM, Jackson-Thompson J, Petroski GF, Schootman M. Reliability of health-related quality-of-life indicators in cancer survivors from a population-based sample, 2005, BRFSS. *Public Health*. 2009;123(4):321–5.

18. Moriarty DG, Zack MM, Kobau R. The Centers for Disease Control and Prevention's Healthy Days Measures—population tracking of perceived physical and mental health over time. *Health Qual Life Outcomes*. 2003;1:37.
19. Centers for Disease Control and Prevention. Measuring Healthy Days: population assessment of health-related quality of life. Atlanta: Centers for Disease Control and Prevention; November 2000.
20. Richardson LC, Wingo PA, Zack MM, et al. Health-related quality of life in cancer survivors between ages 20 and 64 years: population-based estimates from the Behavioral Risk Factor Surveillance System. *Cancer*. 2008;112(6):1380–9.
21. Bieler GS, Brown GG, Williams RL, Brogan DJ. Estimating model-adjusted risks, risk differences, and risk ratios from complex survey data. *Am J Epidemiol*. 2010;171(5):618–23.
22. Meadows AT, Friedman DL, Neglia JP, et al. Second neoplasms in survivors of childhood cancer: findings from the Childhood Cancer Survivor Study cohort. *J Clin Oncol*. 2009;27(14):2356–62.
23. Furner SE, Hootman JM, Helmick CG, et al. Health-related quality of life of US adults with arthritis: analysis of data from the Behavioral Risk Factor Surveillance System, 2003, 2005, and 2007. *Arthritis Care Res*. 2011;63(6):788–99.
24. Trivers KF, Patterson JR, Roland KB, Rodriguez JL. Issues of ovarian cancer survivors in the USA: a literature review. *Support Care Cancer*. 2013;21(10):2889–98.
25. Glaser AW, Fraser LK, Comer J, et al. Patient-reported outcomes of cancer survivors in England 1–5 years after diagnosis: a cross-sectional survey. *BMJ Open*. 2013;3(4):e002317.
26. Albritton KH, Wiggins CH, Nelson HE, Weeks JC. Site of oncologic specialty care for older adolescents in Utah. *J Clin Oncol*. 2007;25(29):4616–21.
27. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355(15):1572–82.
28. Schneider KL, Clark MA, Rakowski W, Lapane KL. Evaluating the impact of non-response bias in the Behavioral Risk Factor Surveillance System (BRFSS). *J Epidemiol Community Health*. 2012;66(4):290–5.
29. Kirchhoff AC, Lyles CR, Fluchel M, et al. Limitations in health care access and utilization among long-term survivors of adolescent and young adult cancer. *Cancer*. 2012;118(23):5964–72.

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