

Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer

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Abstract

Objective: Adolescents and young adults (AYAs) diagnosed with cancer between 15 and 39 years of age often report need for greater amounts of cancer-related information and perceive that cancer has had a negative impact on control over their life. We examined whether unmet information need and perceived control over life are associated with health-related quality of life (HRQOL).

Methods: We examined data from 484 AYA cancer survivors recruited from population-based cancer registries in 2007–2008. Participants completed surveys a median of 11 months after diagnosis. Multivariable linear regression analyses estimated associations of unmet cancer-related information needs and impact of cancer on control over life on HRQOL (SF-12).

Results: Two-thirds of AYAs reported an intermediate or high level of unmet information need, and half (47%) reported a negative impact of cancer on control. Greater unmet information need was associated with lower overall mental and physical HRQOL and lower levels of all HRQOL subscales except vitality. A negative impact on control over life was associated with lower overall mental HRQOL as well as lower HRQOL across all subscales except general health perceptions (all $p < 0.05$). In multivariable analyses, perceived control and unmet information need were independently associated with HRQOL (p -values for interaction > 0.1).

Conclusions: Adolescent and young adult patients with cancer have high levels of unmet cancer-related information needs and perceived negative impact of cancer on control over life; both were independently associated with lower HRQOL. Addressing unmet information needs among AYA cancer survivors and finding ways to increase their sense of control may help improve HRQOL in this understudied population.

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Introduction

Adolescents and young adults (AYAs) diagnosed with cancer between 15 and 39 years of age have the lowest rates of health insurance coverage and the lowest accrual to clinical trials relative to those diagnosed with cancer as children or older adults [1,2]. AYA cancer survivors also encounter a unique set of post-treatment challenges because of their developmental stage, including desire for increased autonomy in familial and other personal relationships, financial independence, changing work/education

settings, issues concerning intimacy/sexuality, and child-rearing [2–4]. Furthermore, like survivors of childhood and adult cancers, AYA survivors are at risk for treatment-related late health effects and disease recurrence that increase with time since treatment [5–7]. Previously published research from the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study found that 53% of respondents had high rates of unmet information needs [8], that 48% reported a negative impact on control over their life after their cancer diagnosis and treatment [9], and that respondents report significantly lower

health-related quality of life (HRQOL) on average than their age-matched counterparts in the general population [10]. Lower HRQOL was associated with having cancer-related symptoms or lacking health insurance at any time since diagnosis, as well as other patient demographic and clinical characteristics [10]. These issues highlight AYAs as a particularly vulnerable group requiring targeted psychosocial and supportive care [1,4,11,12].

Greater amounts of cancer-related information need have been associated with lower mental and physical HRQOL in adult cancer survivors [13], but this association has not been explored in the AYA population. Younger adult cancer survivors report greater information needs than older survivors [13], with information about recurrence risk, potential late side effects, and information about fertility and reproductive risk identified as the most prevalent information needs [11,14]. In addition, a large portion of AYAs report a negative impact of their cancer diagnosis on their sense of control over life [9]. Concepts potentially related to cancer's negative impact on control over life, such as a greater sense of hopelessness [15] and low perceived self-efficacy [16], have been associated with poorer mental status and HRQOL in adult cancer survivors [17–23] but have not been explored in survivors of AYA cancer.

A meta-analysis has reported that HRQOL interventions incorporating components of the social cognitive theory of health promotion result in greater HRQOL improvements [24,25]. Impacts on AYA's sense of control over life may be relevant to multiple aspects of the social cognitive theory of health promotion (perceived self-efficacy, outcome expectations, health goals, or perceived health facilitators and impediments) [26] and knowledge of one's health risks, and the benefits of various health behaviors is a primary component of social cognitive theory [26]. Therefore, examining associations between a negative impact on control over life and HRQOL and between unmet information need and HRQOL will inform interventions to improve HRQOL among AYA survivors.

To investigate associations between impact on control over life or unmet information need with HRQOL, we utilized the first population-based study in the United States that characterizes HRQOL in a large cohort of newly diagnosed AYAs: the AYA HOPE study, sponsored by the National Cancer Institute, with support from LIVESTRONG. We hypothesized that unmet cancer-related information need and negative impact on perceived control over life are associated with decrements in HRQOL. Additionally, given the primacy of unmet information need to the social cognitive theory of health behavior, we hypothesized that impact on control mediates associations between unmet information need and HRQOL.

Methods

Study population and recruitment

Patients were identified through National Cancer Institute population-based Surveillance, Epidemiology and End Results (SEER) cancer registries that cover the geographic areas of Detroit, Michigan; Seattle/Puget Sound, Washington; Los Angeles County, San Francisco/Oakland, Sacramento County, California, and the states of Iowa and Louisiana [27]. Eligibility criteria included a cancer diagnosis between 15 and 39 years of age, residence in the study areas, and a diagnosis date between July 1, 2007 and October 31, 2008 with a first primary cancer diagnosis of non-Hodgkin lymphoma, Hodgkin lymphoma, germ cell cancer (e.g., testicular or ovarian), acute lymphocytic leukemia, or sarcoma (specifically Ewing's sarcoma, osteosarcoma, and rhabdomyosarcoma, excluding tumors arising in the central nervous system) [28]. Those who were not able to read and write English or who were diagnosed on autopsy or death certificate were ineligible. Among 1208 eligible patients, 43% ($n=524$) completed the AYA HOPE survey (one survey was lost). This analysis excluded 23 patients under the age of 18 at the time of survey, because the SF-12 module has only been validated for adults and 16 patients who did not complete all SF-12 HRQOL questions. This resulted in a final study sample of 484. Study approval was obtained by each of the registries' and National Cancer Institute's Institutional Review Boards.

Data collection

The AYA HOPE study included data from SEER registries, a patient survey, and medical records. Potential participants were mailed a study packet and multiple follow-up attempts were made for non-response [27]. Survey questions included demographic characteristics, treatment and symptoms, information needs, the impact of cancer, and psychosocial, physical, and mental functioning. All items were tested and revised (when necessary) during two rounds of one-on-one cognitive interviews ($n=28$). Participants completed the survey a median of 11 months (range from 4 to 22 months) from the date of diagnosis.

Sociodemographic variables

Participants reported their race/ethnicity, education level, and marital status on the patient survey. Hispanic identity was classified separately from all other racial/ethnic groups. Given the small number of American Indian/Alaska Natives (AI/AN) ($n=3$) and that associations with the outcomes of interest were most similar to those for Blacks, these two races/ethnicities were collapsed for the multivariable analyses. Gender was obtained from SEER registries. Marital status was categorized as married

(married or living as married) or unmarried (never married, divorced, separated, and missing).

Medical information

Cancer histology was collected from SEER data and verified via medical records. The medical record forms were specific to the cancer site and assessed information on tumor characteristics and staging, details of surgery, radiation therapy and chemotherapy, whether the patient was currently in treatment, and comorbid conditions. As described previously [29], the number of comorbidities that were considered to be chronic and/or severe (expected to affect treatment or outcomes or to cause a significant health burden) as documented in the medical record were summed for each participant. The number of symptoms (nausea/vomiting, frequent/severe stomach pain, diarrhea/constipation, pain in joints/bones, weight loss, weight gain, frequent/severe fevers, hot flashes, tingling/weakness/clumsiness of the hands/feet, frequent/severe headaches, frequent/severe mouth sores that impact eating/drinking, and problems with memory/attention/concentration) experienced in the last 4 weeks was collected on the survey.

Information needs

The information needs in this study were adapted from questions in a prior study of adult cancer survivors [30] and have been previously described for the AYA HOPE study [8]. Participants were asked if, at the time of the survey, they needed more information about 13 topics: possible long-term side effects of cancer treatment, handling concern about the cancer returning, checking for signs that cancer has returned, handling concern about getting another type of cancer, financial support for medical care, staying physically fit or getting exercise, nutrition and diet, a family member's risk of getting cancer, fertility/reproductive issues, new treatments, complementary and alternative treatments, how to talk about the cancer experience with family and friends, and meeting other adolescents or young adult cancer patients/survivors. Response options 'I need some more information' and 'I need much more information' were collapsed and categorized as unmet need. Response options, 'I have enough information' and 'Does not apply' were collapsed and categorized as a 'met need'. Responses to all 13 information need items were highly correlated (p -value for all possible pairs of items <0.0001) and were thus presented as counts of unmet information need for each patient. Categorizing unmet information need as low (0–3), intermediate (4–8), or high (9–13) balanced a need for sufficient category frequencies to conduct multivariate regression models

while maintaining multiple levels of need to inform associations with outcomes.

Impact on control over life

Impact of cancer on control over life was assessed using one question that was part of an 18-item life impact index designed to identify the positive and negative psychosocial impacts of cancer in AYAs [2,9,11,31]. Individuals were asked to indicate the kind of *overall impact* cancer had on each life domain, including impact on control over life. Response options included does not apply, very negative, somewhat negative, no impact, somewhat positive, and very positive. We grouped responses as negative impact (very negative and somewhat negative), no impact, and positive impact (somewhat positive and very positive) while responses of 'does not apply' were excluded from analyses ($n=13$) as have been done in other studies using this measure [9].

Health-related quality of life (SF-12)

We used the 12-item short-form health survey (SF-12, version 2.0) that has been validated for use in adults 18 and older [32] to assess physical component summary (PCS) and mental component summary (MCS) scores, as well as the following subscales: physical functioning, physical role limitations, bodily pain, general health perception, vitality (energy/fatigue), social functioning, role limitations due to emotional problems, and general mental health.

Statistical analyses

Distributions of selected demographic and clinical characteristics by impact of cancer on control over life and level of information need, as well as the distribution of unmet information need according to impact on control over life, were compared using chi-square tests. Analysis of covariance was used to identify determinants of PCS and MCS scores separately. We further examined associations between impact on control over life and level of information need with physical health subscales (physical functioning, physical role limitations, bodily pain, and general health perceptions) and mental health subscales (vitality, social functioning, emotional role limitations, and general mental health). Covariates considered included those found to be associated with HRQOL among AYA HOPE participants; age, marital status, race/ethnicity, education, cancer site, treatment, treatment status, symptoms, and health insurance status [10]. All multivariable regression models were adjusted for all covariates associated with PCS or MCS at $p < 0.05$; age at survey, gender, race/ethnicity (non-Hispanic White, non-Hispanic Black/AI/AN, Hispanic, and non-Hispanic Asian/Pacific Islanders, education (high school or less,

some college or associate degree, and college graduate or post-graduate), type of cancer, total number of symptoms (0, 1–2, 3–4, and 5+), total number of comorbidities (0, 1, 2+, and unknown), currently in treatment, insurance status, impact on control over life (no impact, negative impact, and positive impact), and level of information need (low, intermediate, and high). We assessed whether impact on control over life and cancer-related information needs interacted in their association with HRQOL and found no interaction (p -values for interaction >0.1). Therefore, all multivariate models present our findings in the absence of this interaction term. All statistical analyses were carried out using SAS software version 9.3 (SAS Institute, Cary, North Carolina). All p -values reported are two-sided, with α set at 0.05.

Results

As reported in Table 1, most study respondents were 20 years of age or older (95%). Over half of the sample was male (64%) and unmarried (57%). Non-Hispanic Whites comprised 59% of the study group, followed by those of Hispanic (21%), Black or American Indian/Alaska Native (10%), and Asian/Pacific Islander race/ethnicity (10%). Most study participants (83%) reported at least one symptom in the last 4 weeks, and 28% had at least one comorbidity recorded in their medical record. An intermediate level of information need was most common among respondents (39%), followed by a low level of information need (33%). Among AYAs responding to the impact of cancer on control over life item ($N=472$), the most common response was a negative impact on control over life (48%), followed by a positive impact (30%). We examined collinearity between unmet information need and control over life. The Pearson's correlation coefficient, significant at $p < 0.05$, was 0.18.

Physical and mental component summary

Hispanic AYAs had significantly lower PCS scores than Whites and AYAs with at least some college reported significantly higher PCS scores than those with less education (Table 2). AYAs diagnosed with sarcoma had lower PCS scores than those with acute lymphocytic leukemia. AYAs reporting three or more symptoms had lower PCS scores and those reporting any number of symptoms had lower MCS scores than those reporting none. AYAs currently in treatment had lower PCS scores. AYA survivors reporting intermediate levels of unmet information need had lower MCS scores (mean (standard deviation (SD))=46.0 (3.6)) than those reporting low levels of unmet information need (mean (SD)=49.1 (3.6)) and AYAs with high levels of unmet information need had lower PCS (mean

(SD)=44.0 (3.1)) and MCS scores (mean (SD)=42.3 (3.6)) than did those reporting low levels of unmet information need (PCS mean (SD)=46.5 (3.1)). AYAs reporting a negative impact on control over their life had lower MCS scores (mean (SD)=47.3 (4.8)) than those reporting no impact on control over life (mean (SD)=53.8 (5.1)).

Physical and mental subscales

AYAs reporting high levels of information need had significantly lower scores on all physical subscales of the SF-12, compared with AYAs reporting low levels of information need (Table 3). These included lower scores on physical functioning (mean (SD)=43.1 (3.2)), physical role limitation (mean (SD)=43.9 (4.1)), bodily pain (mean (SD)=46.5 (3.1)), and general health perceptions (mean (SD)=40.3 (3.5)). AYAs reporting high levels of information need had significantly lower scores on three of four mental subscales than those reporting low information need (Table 3). These included lower scores on social functioning (mean (SD)=43.3 (3.4)), emotional role limitations (mean (SD)=40.8 (3.6)), and general mental health (mean (SD)=41.5 (3.7)).

AYAs reporting a negative impact on control over their life had lower scores on three of four physical subscales and lower scores on all mental subscales than AYAs reporting no impact on control over life. AYAs reporting negative impact on control had lower scores for physical functioning (mean (SD)=39.3 (3.2)), physical role limitation (mean (SD)=40.4 (4.1)), and bodily pain (mean (SD)=46.2 (4.2)). For the mental subscales, AYAs reporting a negative impact on control over life had lower scores for vitality (mean (SD)=45.3 (4.5)), social functioning (mean (SD)=46.0 (4.6)), emotional role limitations (mean (SD)=45.2 (4.9)), and general mental health (mean (SD)=44.8 (4.9)), compared with AYAs reporting no impact on control. Physical and mental subscale scores for AYAs reporting a positive impact on control over their life did not differ from those reporting no impact on control, with one exception. The emotional role limitation subscale had a lower score for AYAs reporting a positive impact on control over life, with a borderline statistical significance for the difference.

Unmet information need was not associated with negative impact on control over life, so our hypothesis postulating impact on control as a mediator of associations between unmet information need and HRQOL was not pursued further.

Discussion

This study is the first, to our knowledge, to consider associations between impact on control over life or unmet information need and HRQOL among AYA cancer

Table 1. Frequency of demographic and clinical characteristics among adolescents and young adults according to level of information need and impact of cancer on control over life^a

	Level of information need ^b				Impact of cancer on control over life				p ^c
	Total (N = 484) n (%)	Low (N = 157) n (%)	Medium (N = 189) n (%)	High (N = 136) n (%)	Negative impact (N = 226) n (%)	No impact (N = 106) n (%)	Positive impact (N = 140) n (%)		
Age at survey									
15–19	25 (5.2%)	16 (10.2%)	7 (3.7%)	2 (1.5%)	12 (5.3%)	6 (5.7%)	7 (5.0%)		
20–29	204 (42.1%)	66 (42.0%)	88 (46.6%)	48 (35.3%)	93 (41.2%)	46 (43.4%)	60 (42.9%)		
30–39	255 (52.7%)	75 (47.8%)	94 (49.7%)	86 (63.2%)	121 (53.5%)	54 (50.9%)	73 (52.1%)	0.02	0.99
Gender									
Male	310 (64.0%)	100 (63.7%)	115 (60.8%)	93 (68.4%)	129 (57.1%)	79 (74.5%)	95 (67.9%)		
Female	174 (36.0%)	57 (36.3%)	74 (39.2%)	43 (31.6%)	97 (42.9%)	27 (25.5%)	45 (32.1%)	0.38	0.01
Race/ethnicity									
Non-Hispanic White	284 (58.7%)	106 (67.5%)	119 (63.0%)	58 (42.6%)	139 (61.5%)	73 (68.9%)	67 (47.9%)		
Non-Hispanic Black/American Indian/Alaska Native	50 (10.3%)	11 (7.0%)	17 (9.0%)	22 (16.2%)	19 (8.4%)	9 (8.5%)	19 (13.6%)		
Hispanic	102 (21.1%)	22 (14.0%)	39 (20.6%)	41 (30.1%)	40 (17.7%)	18 (17.0%)	41 (29.3%)	<0.01	0.01
Non-Hispanic Asian/Pacific Islander	48 (9.9%)	18 (11.5%)	14 (7.4%)	15 (11.0%)	28 (12.4%)	6 (5.7%)	13 (9.3%)		
Education									
High school or less	186 (38.4%)	58 (36.9%)	75 (39.7%)	52 (38.2%)	82 (36.3%)	43 (40.6%)	53 (37.9%)		
Some college or associate degree	133 (27.5%)	36 (22.9%)	51 (27.0%)	45 (33.1%)	68 (30.1%)	28 (26.4%)	34 (24.3%)		
College graduate or post-graduate	165 (34.1%)	63 (40.1%)	63 (33.3%)	39 (28.7%)	76 (33.6%)	35 (33.0%)	53 (37.9%)	0.33	0.73
Marital status									
Married	208 (43.0%)	77 (49.0%)	78 (41.3%)	53 (39.0%)	88 (38.9%)	59 (55.7%)	57 (40.7%)		
Not married	276 (57.0%)	80 (51.0%)	111 (58.7%)	83 (61.0%)	138 (61.1%)	47 (44.3%)	83 (59.3%)	0.17	0.01
Type of cancer by stage									
Acute lymphoblastic leukemia	14 (2.9%)	5 (3.2%)	6 (3.2%)	2 (1.5%)	9 (4.0%)	0	4 (2.9%)		
Germ cell cancer									
Stage I	133 (27.5%)	52 (33.1%)	49 (25.9%)	32 (23.5%)	45 (19.9%)	42 (39.6%)	45 (32.1%)		
Stage II/III/IV	51 (10.5%)	10 (6.4%)	25 (13.2%)	16 (11.8%)	27 (11.9%)	11 (10.4%)	12 (8.6%)		
Stage unknown	10 (2.1%)	4 (2.5%)	1 (0.5%)	5 (3.7%)	3 (1.3%)	4 (3.8%)	3 (2.1%)		
Hodgkin lymphoma									
Stage I	22 (4.5%)	3 (1.9%)	14 (7.4%)	5 (3.7%)	11 (4.9%)	4 (3.8%)	7 (5.0%)		
Stage II/III/IV	112 (23.1%)	44 (28.0%)	43 (22.8%)	24 (17.6%)	57 (25.2%)	16 (15.1%)	33 (23.6%)		
Stage unknown	2 (0.4%)	0	1 (0.5%)	1 (0.7%)	1 (0.4%)	0	1 (0.7%)		
Type of cancer by stage (continued)									
Non-Hodgkin lymphoma									
Stage I	42 (8.7%)	9 (5.7%)	18 (9.5%)	15 (11.0%)	20 (8.8%)	8 (7.5%)	13 (9.3%)		
Stage II/III/IV	78 (16.1%)	25 (15.9%)	25 (13.2%)	28 (20.6%)	44 (19.5%)	18 (17.0%)	15 (10.7%)		
Stage unknown	2 (0.4%)	1 (0.6%)	0	1 (0.7%)	2 (0.9%)	0	0		
Sarcoma	18 (3.7%)	4 (2.5%)	7 (3.7%)	7 (5.1%)	7 (3.1%)	3 (2.8%)	7 (5.0%)		

Table 2. Multivariable linear regression models^a examining SF-12 health-related quality of life outcomes according to cancer-related information need and impact on control over life

	Physical component summary				Mental component summary			
	Beta	Least squares means (±SD)	p for F test	p for difference	Beta	Least squares means (±SD)	p for F test	p for difference
Age (continuous)	-0.008		0.9000		-0.029		0.708	
Gender								
Male	0	42.87 (38.93–46.80)		Reference	0	50.42 (45.86–54.97)		Reference
Female	-0.919	41.95 (37.73–46.16)	0.3432	0.3432	-0.740	49.68 (44.79–54.56)	0.5101	0.5101
Race/ethnicity								
Non-Hispanic White	0	43.37 (39.28–47.45)		Reference	0	48.96 (44.23–53.69)		Reference
Non-Hispanic Black/American Indian/Alaska Native	-0.922	42.45 (37.95–46.94)		0.5095	1.396	50.36 (45.15–55.56)		0.3888
Hispanic	-2.582	40.79 (36.51–45.06)		0.0131	1.541	50.50 (45.55–55.45)		0.2001
Non-Hispanic Asian/Pacific Islander	-0.341	43.03 (38.57–47.48)	0.1013	0.8006	1.410	50.37 (45.21–55.53)	0.5082	0.3681
Education								
High school or less	0	40.84 (36.79–44.90)		Reference	0	50.29 (45.60–54.99)		Reference
Some college or associate degree	2.332	43.18 (39.04–47.32)		0.0188	-0.072	50.22 (45.43–55.02)		0.9498
College graduate or post-graduate	2.356	43.20 (39.04–47.36)	0.0186	0.0138	-0.671	49.62 (44.81–54.44)	0.8087	0.5439
Type of cancer								
Acute lymphoblastic leukemia	0	43.22 (37.41–49.03)		Reference	0	51.57 (44.84–58.30)		Reference
Germ cell cancer	1.803	45.03 (40.81–49.24)		0.4793	-3.564	48.00 (43.12–52.89)		0.2276
Hodgkin lymphoma	0.898	44.12 (40.00–48.24)		0.7235	-3.574	47.99 (43.22–52.77)		0.2243
Non-Hodgkin lymphoma	0.065	43.29 (39.26–47.32)		0.9799	0.101	51.67 (47.00–56.34)		0.9732
Sarcoma	-6.844	36.38 (30.81–41.95)	0.0051	0.0296	-0.571	51.00 (44.54–57.45)	0.0175	0.8753
Currently receiving treatment								
No	0	44.47 (40.35–48.59)		Reference	0	50.53 (45.75–55.30)		Reference
Yes	-4.123	40.35 (36.22–44.48)	0.00105	0.0005	-0.956	49.57 (44.78–54.35)	0.4806	0.4806
Total number of symptoms ^c								
0	0	45.86 (41.32–50.39)		Reference	0	54.56 (49.31–59.82)		Reference
1–2	-0.727	45.13 (41.00–49.25)		0.5431	-2.605	51.96 (47.18–56.74)		0.0603
3–4	-3.816	42.04 (37.81–46.27)		0.0045	-5.450	49.11 (44.22–54.01)		0.0005
5+	-9.253	36.60 (32.62–40.59)	<0.0001	<0.0001	-10.007	44.56 (39.94–49.17)	<0.0001	<0.0001
Total number of comorbidities								
0	0	43.89 (40.04–47.75)		Reference	0	49.33 (44.86–53.80)		Reference
1	-1.939	41.95 (37.67–46.24)		0.0881	1.108	50.44 (45.47–55.40)		0.4000
2+	-1.222	42.67 (38.26–47.08)		0.3576	-1.185	48.15 (43.04–53.26)		0.4415
Unknown	-2.789	41.11 (36.20–46.02)	0.1573	0.0782	2.944	52.27 (46.59–57.96)	0.2242	0.1085
Unknown	-2.789	41.11 (36.20–46.02)	0.1573	0.0782	2.944	52.27 (46.59–57.96)	0.2242	0.1085
Lack of health insurance ^d								
No	0	43.39 (40.03–46.74)		Reference	0	51.39 (47.50–55.28)		Reference
Yes	-1.634	41.76 (37.84–45.67)		0.1527	-3.592	47.80 (43.27–52.33)		0.0068
Missing	-1.313	42.08 (34.97–49.18)	0.3439	0.6875	-0.440	50.95 (42.72–59.18)	0.0255	0.9074

Level of information need ^a	0	46.53 (43.40–49.66)	Reference	0	49.05 (45.43–52.68)	Reference
Low	0	46.53 (43.40–49.66)	0.8965	0	49.05 (45.43–52.68)	0.0051
Medium	-0.123	46.40 (43.33–49.48)	0.0192	-3.088	45.96 (42.41–49.52)	<0.0001
High	-2.568	43.96 (40.83–47.09)	0.0091	-6.790	42.26 (38.64–45.89)	<0.0001
Impact on control over life						
No impact	0	42.29 (37.91–46.66)	Reference	0	53.77 (48.71–58.84)	Reference
Negative impact	-1.443	40.84 (36.67–45.02)	0.1697	-6.448	47.33 (42.49–52.17)	<0.0001
Positive impact	0.471	42.76 (38.64–46.88)	0.1819	-1.467	52.31 (47.54–57.08)	0.2602

^aAll variables presented in Table 1 are included in the multivariable models; age, gender, race/ethnicity, education, type of cancer, current treatment, symptoms, comorbidities, health insurance, unmet information need, and impact on control over life.

^bStatistically significant results are in bold type.

^cReported in the last 4 weeks.

^dConsiders any time since diagnosis without insurance coverage.

^eUnmet need is presented within categories of low (0–3), intermediate (4–8), or high (9–13) unmet information need.

survivors. We found that greater unmet information need and a negative impact of cancer on control over life were highly prevalent in AYAs and were independently associated with lower HRQOL. Specifically, greater unmet information need was associated with lower levels of overall mental and physical health in addition to subscales for physical functioning, physical role limitation, bodily pain, general health perceptions, social function, emotional role limitations, and general mental health. In addition, a negative impact on perceived control over life was associated with lower overall mental HRQOL as well as physical functioning, physical role limitations, bodily pain, vitality, social function, emotional role limitations, and general mental health.

Our finding that unmet information need was associated with lower HRQOL is consistent with previous reports of information need and HRQOL or mood among adult patients in treatment and adult survivors 2–5 years after diagnosis [13,33]. In addition, an intervention study in Scotland involving adults anticipating radiotherapy treatment showed positive effects on mood and lower anxiety among patients receiving high levels of information education compared with patients undergoing standard practice [33]. Providing relevant health information across the age spectrum of survivors is important. AYAs, however, express a particular need for age-appropriate information that takes into account their age, individual cancer, treatments, and side effects/late effects [11]. While we found survey responses to information needs to be highly correlated, the most prevalent unmet information needs among this age group concern treatment, long-term side effects (including fertility), recurrence, and financial support [8,11].

In addition, our findings regarding impact on control over life and lower HRQOL are consistent with studies in young adult survivors of childhood cancer and individuals diagnosed in later adulthood that found helplessness/hopelessness or reduced self-efficacy, concepts potentially related to a negative impact on control over life, to be associated with lower mood or quality of life [17–23,34,35]. Our study highlights the need to further investigate control-relevant concepts in AYA cancer survivors and to determine whether related interventions improve HRQOL. Intervention studies have shown that improvement in self-efficacy is related to better quality of life in adult cancer survivors [19,20]. For example, an intervention comprised of coping skills training for adult cancer patients designed specifically to improve patients’ sense of control over their mental/emotional states was related to improvement in both mood and quality of life [19]. Other promising interventions may include psychosocial counseling or other psychosocial support services [18,20] or may target other aspects of the patient experience relevant to a patients’ sense of control, like

Table 3. Multivariable linear regression models examining SF-12 subscales for health-related quality of life outcomes according to impact on control over life and cancer-related information needs

	SF-12 Physical															
	Physical functioning				Physical role limitations				Bodily pain				General health perceptions			
	Least squares means (±SD)	p for F test	p for difference		Least squares means (±SD)	p for F test	p for difference		Least squares means (±SD)	p for F test	p for difference		Least squares means (±SD)	p for F test	p for difference	
Level of information need ^c																
Low	45.67 (42.47–48.87)	Reference		44.64 (40.32–48.96)	Reference		50.43 (47.29–53.57)	Reference	44.90 (41.36–48.44)	Reference		43.74 (40.27–47.21)	Reference		Reference	
Medium	45.50 (42.35–48.64)	0.8581		40.64 (36.51–44.76)	0.3915		48.90 (45.82–51.99)	0.1086	43.74 (40.27–47.21)	0.1086		41.57 (36.85–46.29)	0.0643		0.2802	
High	43.08 (39.88–46.27)	0.0128	0.0207	43.92 (39.85–47.99)	<0.0001	<0.0001	46.51 (43.37–49.65)	0.0037	40.33 (36.80–43.87)	0.0004	0.0021	40.33 (36.80–43.87)	0.0021	0.0002	0.0002	
Impact on control over life																
No impact	42.66 (38.19–47.14)	Reference		44.64 (40.32–48.96)	Reference		48.21 (43.81–52.60)	Reference	43.77 (38.82–48.71)	Reference		43.77 (38.82–48.71)	Reference		Reference	
Negative impact	39.32 (35.05–43.59)	0.0019		40.64 (36.51–44.76)	0.0001		46.22 (42.03–50.42)	0.0600	41.57 (36.85–46.29)	0.0600		41.57 (36.85–46.29)	0.0643		0.0643	
Positive impact	42.61 (38.39–46.82)	0.0021	0.9599	43.92 (39.85–47.99)	0.0003	0.5151	46.53 (42.39–50.67)	0.2552	45.36 (40.70–50.01)	0.1375	0.0069	45.36 (40.70–50.01)	0.0069	0.2112	0.2112	
	SF-12 Mental															
	Vitality				Social functioning				Emotional role limitations				General mental health			
	Least squares means (±SD)	p for F test	p for difference		Least squares means (±SD)	p for F test	p for difference		Least squares means (±SD)	p for F test	p for difference		Least squares means (±SD)	p for F test	p for difference	
Level of information need ^c																
Low	47.59 (44.21–50.97)	Reference		49.67 (46.23–53.10)	Reference		48.75 (45.11–52.38)	Reference	47.50 (43.85–51.16)	Reference		47.50 (43.85–51.16)	Reference		Reference	
Medium	46.23 (42.91–49.54)	0.1833		46.75 (43.38–50.13)	0.0054		45.73 (42.16–49.29)	0.2806	45.49 (41.90–49.08)	0.2806		45.49 (41.90–49.08)	0.0699		0.0699	
High	45.69 (42.31–49.07)	0.4026	0.1074	43.28 (39.84–46.71)	<0.0001	<0.0001	40.84 (37.21–44.48)	<0.0001	41.50 (37.84–45.15)	<0.0001	<0.0001	41.50 (37.84–45.15)	<0.0001	<0.0001	<0.0001	
Impact on control over life																
No impact	48.82 (44.09–53.54)	Reference		50.69 (45.88–55.50)	Reference		51.98 (46.90–57.06)	Reference	50.80 (45.69–55.91)	Reference		50.80 (45.69–55.91)	Reference		Reference	
Negative impact	45.31 (40.80–49.82)	0.0021		46.02 (41.43–50.61)	<0.0001		45.24 (40.39–50.09)	<0.0001	44.77 (39.89–49.65)	<0.0001		44.77 (39.89–49.65)	<0.0001		<0.0001	
Positive impact	50.15 (45.70–54.60)	<0.0001	0.2723	50.19 (45.67–54.72)	<0.0001	0.6867	49.30 (44.51–54.08)	<0.0001	49.31 (44.50–54.12)	0.0403	0.0001	49.31 (44.50–54.12)	<0.0001	0.2572	0.2572	

^aAll variables presented in Table 1 are included in the multivariable models; age, gender, race/ethnicity, education, type of cancer, current treatment, symptoms, comorbidities, health insurance, unmet information need, and impact on control over life.

^bStatistically significant results are in bold type.

^cUnmet need is presented within categories of low (0–3), intermediate (4–8), or high (9–13) unmet information need.

physician/patient communication [36]. These interventions need to be further evaluated, however, because a recent meta-analysis on the effectiveness of psychosocial therapy on quality of life was inconclusive [37]. Determining approaches to address unmet information needs and the negative impact of cancer on control over life are important to improve the survivorship experience for AYAs. In particular, such interventions should be considered in efforts to improve HRQOL among AYA survivors, perhaps in consideration of the social cognitive theory of health behavior.

Our findings complement other recent analyses of unmet needs and psychosocial health in the AYA HOPE population. HRQOL was found to be lower among AYA survivors than the general population and associated with unmet information needs, unmet service needs, and impact on control over life; all prevalent among AYA cancer survivors [8,10,38]. Furthermore, the documented associations between unmet needs and HRQOL with race/ethnicity, poor/fair perceived quality of care, treatment, and health insurance [8,38] highlight the AYA subgroups most in need of additional support. In another study, AYA cancer survivors reported negative impacts of cancer on other areas of their life besides perceived control over life, including planning for the future (having children and finances), intimacy (dating and sexual function), and feelings about body appearance [9] that may also be associated with HRQOL. While unmet information needs and impact on control over life were independently associated with HRQOL in our analyses, it is possible that other impacts of cancer also may be related to unmet information or service needs [10]. For example, AYAs with a need for more information on talking about cancer were more likely to report cancer having an impact on their personal relationships [39]. In addition, while unmet information need and a negative impact on control over life associate with detriments in HRQOL among AYA survivors, AYA cancer survivors have lower HRQOL than the general AYA population [10], so there are additional areas of need in this population warranting investigation. Future analyses in the AYA HOPE study will continue to reveal important areas for further research and outreach among survivors of AYA cancer.

This study has certain limitations. The generalizability of our findings may be limited by the requirement that participants read and write English and by our overall response rate of 43% (not including patients who participated but did not respond to HRQOL items) [27]. Of potential participants, men and AYAs of Hispanic or Black race/ethnicity (versus non-Hispanic White) were less likely to respond, but respondents did not differ by age, census tract education, median family income, or cancer site from non-participants [27]. However, given that male AYA and AYAs of Black and AI/AN or

Hispanic (versus non-Hispanic White) race/ethnicity were more likely to have unmet information needs [8] and that AYAs unable to read or write English may encounter additional language or cultural barriers to receipt of cancer-related information, we may be underestimating the prevalence of information need in the population of AYA survivors and subsequently its effects on HRQOL. In addition, the psychosocial constructs potentially relevant to impact on control over life are complex. Our impact of cancer survey items are broad and were intended to allow us to determine psychosocial domains that warrant further examination. Our results clearly indicate that the impact on control over life among AYA survivors is an area that needs additional study and could be further examined by different domains of control, including perceived behavioral control, locus of control, and perceived self-efficacy [16]. Investigations of how more specific aspects of control [40,41] are related to HRQOL among AYA survivors may inform targeted interventions focused on the mutable variable of perceived control. It will also be important to evaluate control at multiple points in the cancer trajectory, from diagnosis to long-term survivorship [18], and to determine whether associations with HRQOL change over time.

Our findings suggest that a substantial number of AYA survivors suffer deficits in physical and mental HRQOL related to unmet cancer-related information need or a negative impact of cancer on control over their life. Developmentally appropriate interventions to increase AYAs' understanding of topics related to cancer treatments, long-term side effects, recurrence, financial support, lifestyle factors, and how to interact with others may improve the HRQOL of survivors. Future studies are also needed to determine the relevant aspects of control over life for AYA population and whether control-relevant concepts and their associations with HRQOL change during the course of the cancer experience.

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Conflict of interest

The authors have no conflicts of interest to declare.

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