

PAPER

Perceived impact of cancer among adolescents and young adults: Relationship with health-related quality of life and distress

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Abstract

Objective To examine whether perceptions of the impact of cancer are related to health-related quality of life (HRQoL) and psychological distress among survivors of cancer in adolescence and young adulthood (AYA).

Methods One hundred seventy-three AYA cancer survivors (aged 18-35 and 15-29 years at time of diagnosis) completed a mailed survey assessing impact of cancer (IOC-AYA), HRQoL (SF-36), and distress (BSI-18). Hierarchical linear regression models analyzed the independent effects of perceived impacts of cancer on HRQoL and distress after controlling for clinical and sociodemographic characteristics. Multivariate analyses also examined the extent to which positive and negative perceptions attenuated the effects of control variables on HRQoL and distress.

Results Being unemployed or not in school, and self-reported health problems were significantly associated with worse physical HRQoL. Mental HRQoL and psychological distress appeared as a function of reporting both positive and negative impacts of cancer; mental health outcomes were better in AYAs reporting more positive and less negative impact of cancer in their lives. Perceived impact of cancer, in both positive and negative ways, attenuated the effects of sociodemographic and clinical factors on mental HRQoL and psychological distress.

Conclusion Results suggest that mental HRQoL and psychological distress, but not physical HRQoL, are a function of survivors' perceptions of how cancer has affected them and continues to affect them in both positive and negative ways. Findings suggest that opportunities for AYA cancer survivors to reframe or better understand the context of cancer in their lives may result in improved mental health outcomes.

KEYWORDS

adolescent and young adult, cancer, impact of cancer, oncology, psychological distress, quality of life

1 | INTRODUCTION

Adolescents and young adults (AYAs), aged 15 to 39 years, are in a challenging phase of life marked by developmental transitions such as becoming independent from parents, completing education, pursuing gainful employment, dating, and having children.^{1,2} A cancer diagnosis challenges AYAs' abilities to achieve these developmental milestones.³ For example, changes in physical appearance resulting from treatment (eg, weight changes or hair loss) can negatively impact body image (looking different than peers) and interfere with self-

esteem (avoiding social contacts) and identity development.^{3,4} AYA cancer survivors frequently report concerns regarding sexuality and fertility issues^{5,6} and often experience a diminished feeling of autonomy as they are forced to become dependent on parents or partners.⁷ Furthermore, cancer treatment and late effects can interfere with completing education and getting a job, and thus contributing to increased risk for financial burden.⁸

Confronting the everyday challenges of life as an adolescent or young adult while also coping with a life-threatening disease frequently leads to distress and deleterious effects on one's physical,

psychological, social, and spiritual well-being.^{9,10} Our understanding of cancer's true impact on people, and AYAs in particular, is complemented by studies indicating that many if not most AYAs are resilient, adjust well to their cancer experience, and report personal growth as an outcome of their experience.¹¹⁻¹³ Taken together, this body of work suggests that one's subjective perception or appraisal of cancer's impact on life may be more salient predictors of health-related quality of life (HRQoL) than objective cancer-related characteristics such as cancer type and prognosis for survival.¹²

Psychological theory and brain science suggests that perceptions are a function of a cognitive process in which individuals construct reality. People create and tell stories to themselves and to others to represent a particular phenomenon or experience. While the stories themselves may not reflect an objective truth, they are quite real in their consequences.¹⁴ How one appraises an event is more telling than any externally defined or objective characteristic that others may ascribe to that same event.^{15,16} The evidence base supporting cognitive behavioral interventions with cancer patients is grounded in this notion of appraisal. Extant literature supports the use of cognitive and behavioral approaches to improve HRQoL and reduce psychological distress in cancer patients, often by eliciting patient stories about how cancer has impacted or continues to impact their lives and then assisting them in recreating and retelling those stories as a means of reducing or changing deleterious consequences.¹⁷

The new AYA module of the impact of cancer (IOC) instrument enables examination of the extent to which AYA cancer survivors' perceptions of the IOC in their lives are related to HRQoL and psychological distress.¹⁸ Pediatric and older adult versions of this instrument in research and clinical practice have helped to identify survivors at risk for psychological, social, or behavioral problems related to having had cancer, as well as content areas around which these patients require attention as they move forward in their lives after cancer.^{19,20} Insight into the relationship between perceived IOC and HRQoL is needed to inform the development of psychosocial and supportive care interventions that minimize or prevent long-term deleterious effects of cancer but also promote positive adaptation, resilience, and success in confronting the physical, psychological, social, and spiritual challenges faced by AYA cancer. Therefore, the aims of this study are to (1) assess the association between sociodemographic and clinical characteristics and AYA specific IOC, and (2) examine whether AYA survivors' reported perceptions of IOC on their lives are related to HRQoL and psychological distress, after controlling for clinical and sociodemographic characteristics.

2 | METHODS

2.1 | Design, procedure, and participants

A cross-sectional study was conducted among 551 AYA cancer survivors registered in the tumor registry of the University of Michigan Comprehensive Cancer Center. Study eligibility criteria included AYA cancer survivors who were 15 to 29 years old at time of diagnosis, 18 to 35 years old at time of study, no more than 10 years postdiagnosis, and diagnosis of one of the following invasive cancer

types: Hodgkin's lymphoma, non-Hodgkin's lymphoma, leukemia, testicular cancer, soft tissue sarcomas, and bone tumors (ie, Ewing's, osteosarcoma). These cancers comprise 41% of all invasive cancers in the age range of 15 to 29 years.²¹ All eligible respondents received survey questionnaires, informed consent forms, and a self-addressed and stamped return envelope via US mail. All procedures were approved by the University of Michigan Comprehensive Cancer Center Institutional Review Board.

2.2 | Measures

2.2.1 | IOC-AYA version

The 31-item IOC-AYA was used to measure positive and negative IOC among AYA cancer survivors. Details regarding the development, psychometric evaluation, and scaling of the IOC modules are reported elsewhere.¹⁸⁻²⁰ Seven subscales represent distinct AYA survivor-specific content (social life; uncertainties, worries, and wonders; cognitive function; sense of purpose/life goals; identity; health behaviors; and health literacy). For each item, respondents endorsed the perceived IOC along a five-point Likert scale (0 = strongly disagree; 1 = disagree; 2 = neither agree nor disagree; 3 = agree; 4 = strongly agree). Several items in the subscale were reverse-coded prior to scoring to retain the subscale's positive or negative gradient. Means were calculated for each subscale. Higher scores indicate a greater IOC. Depending upon the respondent's marital/relationship status, skip patterns in the survey guided respondents to 1 of 2 separate and conditional subscales consisting of 7 items each that evaluate "Relationship Concerns". Similarly, dependent upon whether or not the respondent reports having children, 1 of 2 sets of items were used to evaluate impact related to "Having Children." Internal reliability coefficients (Cronbach's alpha) for each of the 7 IOC subscales ranged from 0.70 to 0.90.

Two overarching positive and negative impacts mean scores were also calculated for 17 items suggestive of positive outcomes (Cronbach's alpha = .80) and 14 items suggestive of negative outcomes (Cronbach's alpha = .90).

2.2.2 | Health-related quality of life

Health-related quality of life was measured by the Medical Outcomes Study Short Form-36 Health Survey (SF-36). The SF-36 is a widely used and well-validated instrument that assesses HRQoL²² across 8 dimensions. Internal reliability coefficients (Cronbach's alpha) ranged from .52 to .94. Health-related quality of life is also represented by 2 factor scores: physical health (Physical Component Score [PCS]) and one for mental health (Mental Component Score [MCS]). Raw scores for MCS and PCS were transformed into T-scores ranging from 0 to 100 for purposes of making age-adjusted comparisons. Higher scores represent better QoL.

2.2.3 | Psychological distress

The Brief Symptom Inventory-18 (BSI-18) was used to measure the extent to which a respondent has been bothered by psychological distress symptoms over the past 7 days.²³ Items were measured along a 5-point Likert scale ranging from 0 (not at all) to 4 (extreme). An overall Global Symptom Index (GSI) was calculated. Raw scores for the GSI were converted to age- and sex-adjusted T-scores for comparison to

nonpatient community norms (mean, 50; standard deviation, 10). Higher scores indicate greater distress. Internal reliability coefficient (Cronbach's alpha) of the GSI was .91. An overall GSI score of ≥ 63 suggests caseness for distress.

Sociodemographic and clinical data were collected by patient self-report and included sex, race, employment status, educational attainment, marital/relationship status, age at study, age at diagnosis, and years since diagnosis. Surveillance, Epidemiology, and End Results codes were used to categorize cancer type and then organize them by severity of disease.²⁴ To approximate severity of disease, 3 categories were generated for this study based on epidemiological evidence specific to AYA cancer patients: (1) invasive malignancies with expected 5-year survival rates greater than 80% (eg, Hodgkin lymphoma); (2) malignancies with expected 5-year survival rates of 50% to 80% (eg, osteosarcoma); (3) all other malignancies with expected 5-year survival rates less than 50% (eg, leukemia).²⁵ In addition, respondents were asked to report if they had 1 or more of the following 11 health problems during the past month: shortness of breath; problems with memory, attention, or concentration; frequent or severe stomach pain, pain in your chest (heartburn), or indigestion; ringing in the ears; pain in your joints; weight loss; frequent fevers; lack of sleep or trouble sleeping; frequent tiredness or fatigue; frequent mouth sores that impact your eating and drinking; frequent headaches.

2.3 | Statistical analyses

All statistical analyses were performed using SPSS software, version 22.0 (SPSS Inc., Chicago IL). Two-sided *P* values of <0.05 were considered statistically significant. Differences in sociodemographic and clinical characteristics between respondents and nonrespondents were evaluated using chi-square and independent *t*-tests, where appropriate. Independent *t*-tests were used to compare mean values of IOC subscale scores by sociodemographic and clinical characteristics with 2 values (eg, sex and current health problems). Analysis of variance was used when covariates had more than 2 values (eg, type of cancer). Hierarchical linear regression analyses were then performed separately on 3 outcomes (PCS, MCS, and psychological distress) and included only covariates observed to be significantly associated (at $P < 0.10$) with at least one of the outcomes. Hierarchical linear regression models analyzed the independent effects of these covariates on outcomes. Then, changes in standardized beta coefficients were evaluated when positive and negative IOC scales were added to the regression models.

3 | RESULTS

3.1 | Subjects characteristics

One hundred seventy-three AYA cancer survivors completed and returned useable surveys (31% response rate). No significant differences in age at diagnosis, age at study, or time since diagnosis were observed for respondents and nonrespondents. Respondents were significantly more likely to be of white race (80% vs 70%) and diagnosed

with a hematological disorder (49% vs 37%). Table 1 summarizes demographic and clinical characteristics of respondents.

TABLE 1 Sample descriptives

	Respondents (n = 173)
Age at time diagnosis (SD; range)	21.6(4.0; 15-29)
15-17	36(20.8%)
18-25	107(61.8%)
26-29	30(17.3%)
Age at time survey (SD; range)	27.3(4.3; 18-35)
Sex	
Male	100(57.8%)
Female	73(42.2%)
Race	
White	139(80.3%)
Non-White	11(6.4%)
Unknown or missing	23(13.3%)
Employment Status	
Employed	136(82.4)
Unemployed	29(17.6)
Education	
High school grad or less	16(9.8)
Some college	43(26.2)
Associate degree	19(11.6)
College grad or more	86(52.4)
Partnership Status	
No	78(45.1)
Yes	90(52.0)
Children	
Yes	37(22.3)
No	129(77.2)
Time since diagnosis (SD;range)	5.7(2.6; 2-10)
2-5 years	91(52.6%)
>5 years	82(47.4%)
Cancer type	
Hodgkin lymphoma	59(34.1%)
Non-Hodgkin lymphoma	26(15.0%)
Leukemia	32(18.5%)
Testicular	33(19.1%)
Soft tissue sarcoma	17(9.8%)
Bone tumors	5(2.9%)
Rhabdomyosarcoma	1(0.6%)
Cancer Survival Rate	
80-100%	92(53.2%)
50-80%	48(27.7%)
<50%	33(19.1%)
Health problem interfere daily activities	
No health problem	90(52.6)
Problem but no interference	8(4.7)
Mild interference	59(34.5)
Severe interference	14(8.2)
Health problem other than cancer	
Yes	90(55.2)
No	73(44.8)

TABLE 2 Bivariate comparisons of mean overarching IOC-AYA positive and negative summary subscales by selected independent variables

	Negative Impact Scale	Positive Impact Scale
All respondents	1.5(0.8)	2.9(0.5)
Age at time diagnosis		
15-17	1.5(0.9)	2.9(0.4)
18-25	1.4(0.8)	2.9(0.5)
26-29	1.8(0.9)	2.8(0.6)
<i>P value</i>	0.04	0.51
Sex		
Female	1.6(0.8)	2.9(0.5)
Male	1.3(0.9)	2.8(0.5)
<i>P value</i>	0.03	0.20
Race		
White	1.4(0.9)	2.9(0.5)
Non-White	1.7(0.5)	2.9(0.4)
<i>P value</i>	0.32	0.75
Employment status		
Unemployed	1.8(0.8)	2.7(0.6)
Employed	1.4(0.8)	2.8(0.5)
<i>P value</i>	0.02	0.05
Education		
High school or less	1.7(0.9)	2.6(0.6)
Some college	1.9(1.0)	2.8(0.5)
Associate degree	1.3(0.8)	2.9(0.6)
College grad or more	1.3(0.7)	2.9(0.4)
<i>P value</i>	0.001	0.05
Partner status		
No	1.5(0.9)	2.8(0.6)
Yes	1.4(0.8)	2.9(0.4)
<i>P value</i>	0.46	0.18
Child		
Yes	1.4(0.8)	3.0(0.5)
No	1.5(0.8)	2.8(0.5)
<i>P value</i>	0.59	0.14
Cancer type		
Hodgkin	1.5(0.8)	2.9(0.5)
Non-Hodgkin	1.6(0.9)	2.9(0.6)
Leukemia	1.9(0.8)	2.8(0.4)
Testicular	1.1(0.7)	2.8(0.5)
Soft tissue sarcoma	1.1(0.7)	3.0(0.4)
Bone tumors	1.4(0.8)	3.2(0.6)
<i>P value</i>	0.001	0.36
Cancer survival rate		
80-100%	1.4(0.8)	2.9(0.5)
50-80%	1.4(0.9)	3.0(0.6)
<50%	1.8(0.8)	2.8(0.4)
<i>P value</i>	0.01	0.24
Time since diagnosis		
2-5 years	1.6(0.9)	2.9(0.6)

(Continues)

TABLE 2 (Continued)

	Negative Impact Scale	Positive Impact Scale
>5 years	1.3(0.8)	2.9(0.4)
<i>P value</i>	0.005	0.77
Report current health problems		
Yes	1.8(0.9)	2.7(0.5)
No	1.2(0.7)	3.0(0.5)
<i>P value</i>	<0.001	<0.001
Caseness for distress from BSI-18		
Yes	2.3(0.8)	2.5(0.5)
No	1.3(0.7)	3.0(0.5)
<i>P value</i>	<0.001	<0.001

3.2 | Correlates IOC

Table 2 summarizes the overarching negative and positive IOC summary scales and Appendix 1 the IOC-AYA subscale scores and differences across potential correlates.

3.2.1 | Age at diagnosis

The older aged group reported a significantly higher negative IOC summary score compared to the younger aged groups, mainly reflected by higher scores on social life and uncertainties, worries, and wonders. In addition, the older aged group reported less positive IOC on sense of purpose/goals compared to the younger aged groups. The positive IOC summary score did not differ between age groups.

3.2.2 | Sex

Female AYAs scored significantly higher on the negative IOC summary scale and the subscales uncertainties, worries, and wonders, and cognitive function compared to males. No difference between the sexes was found for the positive IOC summary scale, although female AYAs had a significantly higher score on identity compared to males.

3.2.3 | Race

Nonwhite AYAs reported a higher negative IOC on social life compared to White AYA cancer survivors. No differences in negative or positive summary scores were found.

3.2.4 | Cancer type

Significant differences in IOC were observed across cancer type categories; testicular cancer patients reported less uncertainties, worries, and wonders compared to leukemia patients. And soft-tissue sarcoma and testicular cancer patients reported less negative impact on cognitive function and overall negative impact compared to hematological cancer patients. Testicular cancer patients reported less positive impact on identity compared to non-Hodgkin and bone sarcoma patients. No difference was found in the positive IOC summary score.

3.2.5 | Severity of disease

Those with higher disease severity reported higher negative IOC (social life, cognitive function, and negative summary score). No difference in positive impact summary score was found.

3.2.6 | Time since diagnosis

Reporting a negative IOC was negatively associated with years since diagnosis, in that the likelihood of reporting negative IOC diminished as AYA survivors moved further in time (>5 years) from their diagnosis. This difference is mainly reflected in the domains social life and uncertainties, worries, and wonders.

3.2.7 | Educational level and employment status

Employment status and educational attainment were significantly associated with negative impacts of cancer, with higher scores for those unemployed and with a lower educational level. Being employed was associated with higher positive IOC on sense of purpose/goals and health behavior; the last one was also higher for those with a higher educational attainment.

3.2.8 | Partnership status and having children

No significant effects were found for partnership status and having children.

3.2.9 | Health problems and distress

Survivors reporting health problems or high levels of psychological distress had statistically higher negative and lower positive IOC scores.

3.3 | Associations between IOC and HRQoL and distress

Three multivariate hierarchical regression models reporting standardized beta coefficients for each outcome (PCS, MCS, and psychological distress) were conducted (Table 3). Occupational/school status, disease severity, and current health problems were significantly associated with PCS and maintained significant throughout all models. Negative and positive IOCs were not associated with PCS scores, while they were significantly associated with MCS and psychological distress. Age at time diagnosis, sex, and educational level were significantly associated with MCS scores in model 1, but these effects were attenuated (even not significant for educational level anymore) once accounting for negative and positive impacts of cancer. Similarly, employment status, educational level, and current health problems were significantly associated with psychological distress, but these effects diminished when negative and positive impacts were added to the model.

4 | DISCUSSION

The primary aim of this study was to examine the extent to which negative and positive perceptions of cancer's impact on AYA cancer survivors' lives influence the quality of their lives. Our results reinforce the notion that perceptions are real in their consequences. The standardized beta coefficients for positive and negative subscales reported here

suggest that the relative impact of positive and negative perceptions on AYA cancer survivors' HRQoL and psychological distress was greater than the effect of any other demographic or cancer-specific correlate, a finding consistent with studies of cancer survivors of varied ages.^{12,26–28} The results highlight that how AYA cancer survivors appraise their cancer experience, how they view themselves as cancer patients or survivors, and how well they are able to solve a problem and reengage with goals are associated with how they adapt to the experience.

The variability of negative and positive IOCs in AYA cancer survivors suggests that survivor characteristics, inclusive of age, sex, employment status, educational level, cancer type, disease severity, time since diagnosis, current health problems, and psychological distress, have unique and specific associations with different aspects of IOC. This finding indicates that some AYA cancer survivors are more in need of programs to reframe perceptions. For example, older AYA cancer survivors reported higher negative IOC, which may have to do with higher work-related and social demands and more responsibilities (partner, children) at time of diagnosis. Educational attainment and occupational status also appeared to be associated with IOC. Not being successful to attain life goals such as finishing school may result in feelings of abnormality, problems in social life, and more worries, while being successful in getting a job may contribute to survivors feeling like their lives are normal after having had cancer, which is also reflected by the higher scores on "sense of purpose/goals in life". Differences in IOC between tumor types might be explained by differences in intensity of treatment, number, and kind of debilitating ongoing symptoms and late effects, length of hospital stay, and chance of disease recurrence. Furthermore, consistent with prior research, negative IOC decreased over time. This could be explained by the fact that for most cancer survivors who resumed their lives after cancer, the number of reminders of cancer decreases. Those who experience current health problems (potential reminders of cancer²⁹) or distress had more negative and less positive IOC. These last results suggest that posttreatment symptom and distress management may also be helpful to decrease negative and increase positive IOCs. Reducing health problems may also have a direct positive effect on physical HRQoL.

4.1 | Clinical implications

Because perceptions are malleable, cognitive behavioral therapy and/or peer support programs may help to reframe negative perceptions and promote positive perceptions and will thereby potentially enhance well-being outcomes for AYA cancer survivors.^{8,30} Programs and services that offer opportunities for AYAs to tell their stories and share their challenges, struggles, and successes with others have already proven to be powerful interventions that promote the quality of AYAs lives.³¹ These opportunities, coming in the form of oncology camps or retreats and social meet-ups, may serve as experiences or cues that reinforce positive adaptation and, for some, facilitate posttraumatic growth or thriving—the notion that one's life is renewed, renormalized, or perhaps even better for having overcome cancer.

TABLE 3 Multivariate hierarchical linear regression analyses of the association between IOC-AYA summary scales and HRQoL and psychological distress (standardized betas are presented)

	PCS			MCS			Psychological Distress		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Age									
15-17	-0.13	-0.15	-0.15	0.22*	0.08	0.05	-0.09	0.05	0.07
18-25	-0.11	-0.13	-0.12	0.30**	0.16	0.19*	-0.13	0.01	-0.01
>26	ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Sex									
Female	-0.02	-0.01	-0.01	-0.18*	-0.07	-0.13*	0.07	-0.04	0.01
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Race									
White	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Non-White	-0.01	-0.01	-0.01	-0.01	0.03	0.01	-0.02	-0.03	-0.01
Partnership status									
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	-0.09	-0.10	-0.10	0.15	0.09	0.04	-0.05	-0.01	0.02
Employment status									
Unemployed	-0.25**	-0.25**	-0.25**	-0.16	-0.14	-0.11	0.15*	0.14*	0.12*
Employed	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Education									
Some college or less	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Associate degree or higher	0.14*	0.13	0.13	0.18*	0.04	0.03	-0.26**	-0.14*	-0.14*
Cancer survival rate									
80-100%	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
50-80%	-0.11	-0.11	-0.11	0.10	0.12	0.07	-0.03	-0.03	0.01
<50%	-0.18*	-0.18*	-0.18*	0.08	0.13	0.10	-0.01	-0.06	-0.04
Report current health problems									
Yes	-0.34**	-0.33**	-0.33**	-0.09	0.01	0.07	0.24**	0.12*	0.08
No	ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Negative impact scale		-0.06	-0.05		-0.54**	-0.39**		0.55**	0.45**
Positive impact scale			0.03			0.38**			-0.26**
Model F value	8.56	7.92	7.32	3.76	8.46	11.95	6.58	14.28	16.09
Overall model significance	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001
Adjusted R2	0.42	0.42	0.42	0.24	0.44	0.55	0.36	0.57	0.62
Change in R2		0.0	0.0		0.20**	0.11**		0.21**	0.05**

Mental component score, MCS, PCS, physical component score.

* $P < 0.05$

** $P < 0.01$.

4.2 | Study limitations

The cross-sectional study design limits the ability to determine direction of causation. For example, we cannot determine whether perceptions of the cancer experience influence or are influenced by HRQoL and psychological distress, or if both are true. Reliance on self-report data of clinical characteristics (eg, tumor type) and lack of data from medical records or other objective sources (eg, treatment modalities, history of relapse, metastatic disease, treatment-related late effects) also tempers our findings, as these conditions may be related to HRQoL outcomes. The response rate and inclusion of only a selected group of tumor types (only 41% of all invasive cancers in the AYA age range were covered, primarily lower risk cancers among higher educated and employed, white survivors) and age range (15-29 years at diagnosis)

also limit the generalizability of our findings, although respondents were representative of the entire sample pool for age at diagnosis, age at study, time since diagnosis, and sex. Limited response rate is a common problem in studies involving AYAs,^{32,33} partially reflecting the difficulty in locating and recruiting a geographically mobile young adult population that in most cases is many years beyond therapy and no longer living with their parents. Reporter bias cannot be excluded as cancer survivors may be likely to over report on what they think is important. Longitudinal studies are needed to establish evidence of causality, which could lead to the refinement of psychotherapeutic approaches that will ultimately enhance HRQoL in AYA cancer survivors. In addition, attention needs to be paid to the management of current health problems and helping AYAs to get back to work or get a job as these factors were strongly associated with physical well-being.

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APPENDIX
Appendix 1. Bivariate comparisons of mean scores of IOC-AYA subscales by selected independent variables

	Negative Impact of Cancer			Positive Impact of Cancer			Conditional Scales				
	Social Life	Uncertainties, Worries, and Wonders	Cognitive Function	Identity	Health Behavior	Health Literacy	Sense of Purpose/Goals	RP (n = 90)	RNP (n = 78)	HV (n = 37)	NHV (n = 129)
All respondents	1.1 (1.0)	1.7 (1.0)	1.9 (1.3)	2.8 (0.7)	2.7 (0.7)	2.8 (0.7)	3.1 (0.8)	1.3 (0.7)	1.5 (0.9)	1.4 (1.0)	1.7 (0.8)
Age at time diagnosis											
15-17	1.3 (1.0)	1.6 (1.1)	1.7 (1.3)	2.8 (0.8)	2.8 (0.8)	2.8 (0.7)	3.4 (0.6)	1.4 (0.7)	1.4 (0.8)	Na	1.6 (0.8)
18-25	1.0 (1.0)	1.6 (0.9)	1.9 (1.3)	2.8 (0.7)	2.7 (0.7)	2.8 (0.7)	3.2 (0.8)	1.3 (0.7)	1.6 (0.9)	1.4 (0.8)	1.7 (0.8)
26-29	1.4 (1.0)	2.1 (1.0)	2.1 (1.5)	2.9 (0.8)	2.6 (0.7)	2.9 (0.8)	2.8 (1.2)	1.5 (0.8)	2.0 (0.9)	1.5 (1.1)	1.6 (1.0)
P value	0.046	0.032	0.49	0.77	0.51	0.66	0.014	0.35	0.32	0.74	0.89
Sex											
Female	1.2 (0.9)	1.9 (0.8)	2.1 (1.3)	3.0 (0.7)	2.7 (0.7)	2.8 (0.7)	3.1 (0.7)	1.5 (0.7)	1.6 (0.9)	1.5 (0.9)	1.9 (0.8)
Male	1.1 (1.0)	1.5 (1.0)	1.7 (1.3)	2.6 (0.8)	2.7 (0.8)	2.8 (0.8)	3.1 (0.9)	1.2 (0.7)	1.5 (0.9)	1.3 (1.0)	1.6 (0.8)
P value	0.34	0.01	0.03	0.001	0.73	0.98	0.99	0.06	0.93	0.47	0.03
Race											
White	1.0 (1.0)	1.6 (1.0)	1.9 (1.4)	2.8 (0.8)	2.8 (0.7)	2.9 (0.7)	3.2 (0.8)	1.3 (0.7)	1.5 (0.9)	1.4 (1.0)	1.6 (0.9)
Non-White	1.3 (0.9)	1.9 (0.6)	2.1 (1.2)	2.9 (0.7)	2.7 (0.7)	2.7 (0.4)	3.1 (0.9)	1.3 (0.5)	1.4 (0.5)	1.3 (0.4)	1.9 (0.3)
P value	0.024	0.06	0.77	0.87	0.24	0.38	0.54	0.92	0.15	0.93	0.07
Employment status											
Unemployed	1.7 (1.0)	1.7 (1.0)	2.3 (1.4)	2.6 (0.7)	2.5 (0.9)	2.9 (0.7)	2.8 (1.1)	1.7 (0.8)	1.5 (1.1)	1.9 (0.8)	1.8 (1.0)
Employed	1.0 (1.0)	1.7 (1.0)	1.8 (1.3)	2.8 (0.8)	2.8 (0.7)	2.8 (0.8)	3.2 (0.8)	1.3 (0.6)	1.5 (0.9)	1.4 (1.0)	1.7 (0.8)
P value	0.001	0.66	0.034	0.27	0.024	0.39	0.017	0.015	0.96	0.24	0.54
Education											
High school or less	1.6 (1.0)	1.7 (1.0)	2.0 (1.3)	2.3 (0.9)	2.2 (0.9)	3.1 (0.7)	2.8 (1.1)	1.6 (0.9)	1.4 (0.7)	0.6 (0.1)	1.9 (0.8)
Some college	1.5 (1.1)	2.1 (1.1)	2.2 (1.4)	2.9 (0.7)	2.6 (0.8)	2.9 (0.7)	3.0 (1.0)	1.5 (0.7)	2.0 (0.9)	1.8 (1.1)	2.1 (0.8)
Associate degree	1.0 (1.2)	1.4 (0.8)	1.9 (1.6)	2.8 (0.8)	2.9 (0.7)	2.7 (0.8)	3.1 (0.9)	1.5 (0.5)	1.3 (1.1)	1.4 (0.9)	1.6 (0.7)
College grad or more	0.8 (0.8)	1.5 (0.9)	1.7 (1.3)	2.8 (0.7)	2.9 (0.6)	2.8 (0.8)	3.3 (0.6)	1.2 (0.6)	1.4 (0.8)	1.4 (1.0)	1.5 (0.8)
P value	0.001	0.011	0.15	0.080	0.003	0.44	0.057	0.11	0.06	0.39	0.003
Partner status											
No	1.3 (1.0)	1.7 (1.0)	1.8 (1.3)	2.8 (0.8)	2.7 (0.8)	2.8 (0.7)	3.0 (0.9)	NA	1.6 (0.9)	2.2 (1.2)	1.8 (0.8)
Yes	1.0 (0.9)	1.7 (0.9)	1.9 (1.4)	2.8 (0.8)	2.8 (0.6)	2.9 (0.7)	3.3 (0.8)	1.3 (0.7)	NA	1.4 (1.0)	1.6 (0.8)
P value	0.10	0.99	0.66	0.70	0.29	0.81	0.06	NA	NA	0.28	0.35
Child											
Yes	0.9 (0.8)	1.8 (1.0)	1.8 (1.5)	2.9 (0.8)	2.7 (0.7)	3.1 (0.7)	3.2 (0.9)	1.3 (0.7)	1.4 (0.7)	1.4 (1.0)	NA

(Continues)

TABLE (Continued)

	Negative Impact of Cancer			Positive Impact of Cancer				Conditional Scales			
	Social Life	Uncertainties, Worries, and Wonders	Cognitive Function	Identity	Health Behavior	Health Literacy	Sense of Purpose/Goals	RP (n = 90)	RNP (n = 78)	HV (n = 37)	NHV (n = 129)
No	1.2 (1.0)	1.6 (0.9)	1.9 (1.3)	2.7 (0.7)	2.7 (0.7)	2.8 (0.7)	3.1 (0.8)	1.3 (0.6)	1.6 (0.9)	NA	1.7 (0.8)
P value	0.10	0.46	0.72	0.36	0.85	0.02	0.46	0.96	0.74	NA	NA
Cancer type											
Hodgkin	1.1 (1.0)	1.8 (0.9)	1.8 (1.3)	2.8 (0.7)	2.7 (0.7)	2.9 (0.8)	3.2 (0.8)	1.2 (0.7)	1.5 (0.8)	1.4 (1.1)	1.8 (0.7)
Non-Hodgkin	1.3 (1.1)	1.7 (1.0)	2.5 (1.3)	3.0 (0.7)	2.7 (0.7)	2.9 (0.7)	3.0 (0.9)	1.4 (0.7)	1.5 (0.9)	1.4 (1.0)	1.6 (0.8)
Leukemia	1.5 (1.0)	1.9 (0.9)	2.7 (1.1)	2.9 (0.6)	2.6 (0.7)	2.7 (0.7)	3.0 (0.8)	1.7 (0.7)	1.9 (0.9)	1.4 (0.2)	2.0 (1.0)
Testicular	0.9 (0.9)	1.1 (1.0)	1.3 (1.1)	2.4 (0.8)	2.8 (0.8)	3.0 (0.8)	3.1 (0.9)	1.2 (0.7)	1.6 (1.0)	1.2 (1.4)	1.4 (0.7)
Soft tissue sarcoma	0.8 (0.8)	1.6 (0.8)	0.8 (0.9)	2.9 (0.8)	3.1 (0.5)	2.7 (0.7)	3.4 (0.7)	1.3 (0.8)	1.0 (0.8)	1.5 (0.8)	1.1 (1.0)
Bone tumors	0.8 (0.8)	1.8 (0.7)	1.9 (1.8)	3.4 (0.7)	2.7 (1.2)	3.0 (0.9)	3.8 (0.6)	NA	0.9 (0.7)	NA	1.8 (1.1)
P value	0.06	0.009	<0.001	0.008	0.29	0.70	0.25	0.37	0.17	0.99	0.02
Cancer survival rate											
80%-100%	1.0 (0.9)	1.6 (1.0)	1.6 (1.3)	2.7 (0.8)	2.7 (0.7)	2.9 (0.8)	3.1 (0.8)	1.2 (0.7)	1.5 (0.9)	1.3 (1.2)	1.7 (0.7)
50%-80%	1.1 (1.0)	1.7 (0.9)	1.8 (1.5)	3.0 (0.7)	2.8 (0.7)	2.8 (0.7)	3.2 (0.9)	1.4 (0.7)	1.2 (0.8)	1.5 (0.9)	1.5 (0.9)
<50%	1.5 (1.0)	1.9 (0.9)	2.6 (1.1)	2.8 (0.6)	2.6 (0.7)	2.7 (0.7)	3.0 (0.8)	1.7 (0.7)	1.9 (0.9)	1.4 (0.2)	2.0 (1.0)
P value	0.045	0.22	0.003	0.048	0.36	0.47	0.64	0.09	0.06	0.90	0.07
Time since diagnosis											
2-5 years	1.3 (1.0)	1.8 (1.0)	2.0 (1.3)	2.8 (0.7)	2.7 (0.7)	2.9 (0.7)	3.0 (1.0)	1.4 (0.7)	1.7 (0.9)	1.6 (1.1)	1.8 (0.8)
>5 years	0.9 (0.9)	1.5 (0.9)	1.8 (1.4)	2.8 (0.8)	2.8 (0.7)	2.8 (0.8)	3.2 (0.6)	1.3 (0.7)	1.4 (0.8)	1.3 (0.8)	1.5 (0.9)
P value	0.008	0.008	0.45	0.46	0.25	0.47	0.15	0.85	0.10	0.45	0.10
Report current health problems											
Yes	1.5 (1.1)	2.0 (1.0)	2.2 (1.4)	2.8 (0.7)	2.4 (0.8)	2.6 (0.8)	3.0 (0.9)	1.5 (0.7)	2.1 (0.9)	1.8 (0.9)	2.0 (0.8)
No	0.8 (0.8)	1.4 (0.9)	1.5 (1.2)	2.8 (0.8)	3.0 (0.6)	3.0 (0.7)	3.3 (0.7)	1.2 (0.6)	1.2 (0.8)	1.2 (1.0)	1.5 (0.8)
P value	<0.001	<0.001	0.001	0.75	<0.001	0.002	0.049	0.042	<0.001	0.09	0.005
Caseness for distress from BSI-18											
Yes	2.1 (1.1)	2.3 (0.9)	2.7 (1.2)	2.8 (0.8)	2.2 (0.7)	2.7 (0.9)	2.5 (1.1)	1.9 (1.0)	2.3 (0.8)	1.6 (0.9)	2.0 (0.9)
No	0.9 (0.8)	1.5 (0.9)	1.7 (1.3)	2.8 (0.7)	2.9 (0.7)	2.9 (0.7)	3.3 (0.7)	1.2 (0.6)	1.3 (0.8)	1.4 (1.0)	1.6 (0.8)
P value	<0.001	<0.001	<0.001	0.68	<0.001	0.13	<0.001	0.001	<0.001	0.74	0.009