What a Pain: The Impact of Physical Symptoms and Health Management on Pursuit of Personal Goals Among Adolescents with Cancer

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Purpose: This study examined health-related hindrance (HRH) of personal goals among adolescents receiving treatment for cancer and healthy peers.

Methods: Adolescents and parents completed measures of demographics and psychosocial variables. Adolescents reported on their HRH, measured by ratings of the impact of pain, fatigue, other physical symptoms, and doing things to manage their health on self-identified personal goals. Disease-related information was abstracted from patient charts.

Results: Adolescents with cancer experienced significantly more HRH than healthy peers, and their HRH was significantly associated with poorer health-related quality of life ($p < 0.001$), negative affect ($p = 0.03$), and depressive symptoms ($p = 0.03$). Risk and resilience factors associated with HRH for those with cancer included pain (current and past month severity, frequency, and pain-related quality of life), fatigue, nausea, cognitive problems, worse parent-reported family functioning, and female gender. When testing these significant associates in a regression model predicting HRH among adolescents with cancer, those with more severe pain ($p < 0.001$) and worse parent-reported family functioning ($p = 0.01$) were significantly associated with HRH; fatigue was marginally ($p = 0.09$) significant.

Conclusions: Results suggest that HRH is a significant problem for adolescents with cancer, particularly those who are experiencing pain. Addressing pain and other symptom management, enhancing family functioning, and helping adolescents adjust their goals or enhance support for goal pursuit may reduce HRH among adolescents with cancer. This may improve psychosocial well-being, address adolescent unmet needs, and ultimately help adolescents with cancer maintain normal developmental trajectories.

Keywords: health-related quality of life, psychosocial, pain management, morbidity, supportive care

Introduction

ADOLESCENTS WITH CANCER face significant health-related and psychosocial challenges. Their treatment is often more intense and associated with more toxicity and morbidity than younger patients.^{1–3} More than half of adolescents with cancer report experiencing pain, fatigue, and nausea.⁴ These symptoms persist across diagnoses, treatment modalities, and stage of disease, and can result from treatment, the cancer itself, or an unknown origin.^{5–13} These aversive symptoms and other cancer-related disruptions (e.g., hospitalizations, appointments, adherence demands, and facing a life-threatening condition) during adolescence may impact normative developmental processes, including goal setting and pursuit.

Goals refer to internal representations of desired states¹⁴ that span different areas of functioning and developmental tasks. For example, adolescents may set and pursue goals related to relationships with friends, family, and romantic partners; academics and occupational aspirations; and leisure activities.^{15,16} Health-related hindrance (HRH) refers to the impact of health on pursuing and achieving personal goals.^{17,18} A strength of HRH as a measurement of adolescent adjustment is that it measures what is personally salient to the adolescent during a developmental period of increasing goal setting and autonomy, rather than a standardized set of functional outcomes or activities found on many health-related quality of life (HRQOL) measures.¹⁷ HRH is also a construct that can relate to adolescents and adults who are healthy and ill as it assesses

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the impact of physical health (e.g., pain, fatigue) and behaviors that may be salient for anyone.

Long-term survivors with late effects experience greater HRH than healthy peers, and HRH is associated with poor well-being and HRQOL.¹⁵ Adolescents with cancer also report that the majority of their goals are similar in content to healthy adolescents.¹⁹ In particular, when asked to list personal goals, adolescents with cancer identified just as many academic, occupational, body and appearance, interpersonal, religious, administrative, and future-oriented goals as healthy peers. However, adolescents with cancer identified significantly more health-related and intrapersonal goals, and significantly fewer goals related to leisure activities, compared to healthy adolescents.¹⁹ Taken together, these findings indicate that the experience of having cancer can disrupt adolescents' pursuit of developmentally normative goals.¹⁹ However, little is known about the impact of cancer-related symptoms or disease management on adolescents' goal pursuit while they are undergoing treatment for cancer, and whether individual differences in disease-related and psychosocial factors play a role in vulnerability or resilience to HRH.

Understanding HRH among adolescents undergoing treatment for cancer is important for many reasons. They are an underserved and understudied population with unmet needs^{20–22}; often experience delays in developmental tasks such as living independently, completing education, and having romantic relationships that may be, in part, due to the impact of cancer on goal pursuit during adolescence^{23,24}; and they are at higher risk for adverse psychosocial outcomes than patients diagnosed at younger ages.²⁵ Furthermore, constructs similar to HRH such as reprioritization of goals, discrepancy between goal importance and achievability, and disturbed goals have been linked to adjustment in cancer patients.^{26,27} A longitudinal study in adults with cancer also found an association between goal disturbance and steeper cortisol awakening response, which is associated with adverse health outcomes.²⁵ Thus, HRH, or the factors that impact HRH, may serve as important intervention targets to address unmet needs, reduce the functional impact of treatments, and improve the long-term HRQOL, developmental outcomes and possibly health outcomes of adolescents with cancer. Understanding the prevalence of and burden of HRH, relative to never ill adolescents, and characteristics of those most at risk for HRH is a critical first step.

The disability-stress-coping model²⁸ is a well-validated model of adaptation to childhood chronic illness that informed our investigation. It considers how the interplay of disease-related and psychosocial factors confers risk and resilience for maladjustment. In particular, the model purports that a patients' risk for maladaptive outcomes is influenced by their physical symptoms and disease management demands, intrapersonal factors (e.g., motivation and self-efficacy), stress processing approaches (e.g., coping skills), and social-ecological factors (e.g., family environment). This model provides a guiding framework to identify factors that may be associated with HRH—a marker of potential problematic adaptation to a cancer diagnosis and later maladjustment.

The present study builds on prior work on personal goals among youth with cancer by focusing on adolescents undergoing active treatment for cancer, examining the association between HRH and functioning, testing disease-related and psychosocial predictors of HRH, and using a comparison

group of healthy adolescents. The first aim was to demonstrate the problem of HRH in adolescents with cancer by testing two hypotheses: (1) adolescents with cancer experience more HRH than healthy controls and (2) among adolescents with cancer, HRH is associated with other adverse outcomes such as lower HRQOL, more depressive symptoms, more negative affect, and less positive affect. The second aim was to identify associates of HRH following the disability-stress-coping model.²⁶ It was expected that disease-related factors would place adolescents at risk for greater HRH and that psychosocial factors such as adaptive stress processing approaches (more active coping and positive reframing strategies), intrapersonal factors (higher self-efficacy and higher dispositional hope), and social-ecological factors (more family and peer support, higher family functioning) would confer resilience to HRH.

Method

The study received approval from the institutional review board at the pediatric hospital where the research took place.

Participants

Adolescents aged 13 to 19 years with cancer ($n = 102$) and healthy control participants ($n = 97$) completed the study with a primary caregiver.²⁹ Inclusionary criteria for all participants included English speaking and cognitively able to complete questionnaires. Eligible adolescents with cancer were on active treatment (not terminal) and at least 1 month since diagnosis. Potential control participants were ineligible if they ever had a chronic or life-threatening health condition, acute problem requiring hospitalization, or immediate family member with a chronic or life-threatening health condition.

Procedures

Eligible participants with cancer were identified via clinic and inpatient rosters and the tumor registry, and approved to be approached by a member of the patient's medical team. Potential participants were approached on outpatient ($n = 38$) and inpatient ($n = 64$) floors. Participants with cancer did not differ on HRH by location of recruitment. We recruited healthy controls via flyers in a hospital office building or by snowball recruitment strategy,²⁹ through which participants were asked to distribute flyers to invite potential controls. Healthy participants who were referred by adolescents with cancer ($n = 32$, 33%) or healthy adolescents ($n = 33$, 34%), or opted-in after seeing a flyer ($n = 32$, 33%), did not differ on psychosocial variables. Caregivers and adolescents (age >18) provided consent; adolescents <18 provided assent. Questionnaires were completed at the hospital or home. Adolescents were paid \$25.

Measures

Caregivers completed a demographic form to ascertain the adolescent's age, sex, race/ethnicity, household income, and household composition. We used household income and composition to calculate a binary variable representing families with an income-to-needs ratio above (higher income) or below (lower income) 200% of the poverty status cutoff according to Federal Poverty Guidelines.^{30,31} Adolescents and caregivers completed measures of psychosocial well-being.

Health-related hindrance (full sample). The Health-Related Hindrance Inventory¹⁷ prompts participants to think about goals and write up to 10 of their “most important” goals. They then rate the impact of pain, fatigue, and other physical symptoms and health problems (e.g., nausea, infection), and doing things to take care of health problems (e.g., going to doctor or hospital, taking medicine) on their ability to pursue and achieve each goal using a scale of 0 = *no effect* to 6 = *extreme effect*. For example, “How much does pain interfere with your ability to pursue and achieve your goal of [insert patient goal]?” The average of these ratings across goals forms four subscales (α ranged from 0.89 to 0.94). The average of all ratings yields a total HRH score ($\alpha = 0.93$). More details of the content and appraisals of the goals are reported elsewhere.¹⁹ In addition to demonstrating good internal consistency, this measure has shown good construct validity in samples of survivors of pediatric cancer, youth with other chronic illnesses, and healthy youth.^{17,32}

Psychosocial well-being (full sample). The Positive and Negative Affect Scale is a 20-item self-report inventory with subscales of positive and negative affect.³³ The 10-item short-form of the Child Depression Inventory assessed depressive symptoms in the past 2 weeks.³⁴ Total scores were converted to T-scores based on sex and age norms. Adolescents and caregivers completed the Pediatric Quality of Life Scale (PedsQL) to assess adolescents’ frequency of problems with emotional, social, and school functioning.^{35,36} A standardized total score was computed, with higher scores indicating better HRQOL.

Disease-related factors (cancer group only). Medical record review identified diagnosis (categorized as leukemia, lymphoma, solid tumor, or brain tumor), months since diagnosis, relapse status, treatment, and number of days spent inpatient. Two pediatric oncology providers used chart abstractions and the well-validated Intensity of Treatment Rating–2 system³⁷ to rate treatment intensity on a 4-point scale of *least* to *most intensive*. A third pediatric oncologist reviewed

and identified 10 discrepant ratings that were easily resolved. Ratings of *least* and *moderate* were collapsed due to few ratings of *least* intense. Perceived life threat was assessed using an item adapted from the Assessment of Life Threat and Treatment Intensity Questionnaire for adolescents—“I could die from my cancer.”³⁸ Three items of the Varni/Thompson Pediatric Pain Questionnaire assessed current pain severity, and frequency and severity of pain in the past 4 weeks.³⁹ The Multidimensional Fatigue Scale is an 18-item self-report questionnaire with a subscale representing general fatigue.³⁵ Higher scores indicate less fatigue. The adolescent version of the PedsQL cancer module yields three subscales used in the current analyses (pain, nausea, and cognitive problems), with higher scores indicating better functioning.³⁵

Psychosocial factors (cancer group only). *Stress processing approaches*. The Brief COPE is a well-validated self-report measure of coping with several subscales.⁴⁰ The Positive Reframing and Active Coping Strategies subscales were used, with higher scores indicating greater use of the coping style.

Intrapersonal characteristics. The Cowen Self-Efficacy Scale is a 20-item self-report questionnaire that measures general self-efficacy, with higher scores indicating greater self-efficacy.⁴¹ The Children’s Hope Scale is a 6-item self-report questionnaire that assesses dispositional hope.⁴² Higher scores represent more hope.

Social–ecological factors. Adolescents and caregivers completed the 12-item General Functioning subscale of the Family Assessment Device, with higher scores representing worse functioning.^{43,44} The Family and Friends versions of the Perceived Social Support Scale are each 20-item self-report questionnaires, with higher scores indicating greater support.⁴⁵

Data analysis plan

We conducted descriptive statistics and histograms to examine variables for normal distribution of residuals and for outliers in the full sample and in the cancer group only.

TABLE 1. DEMOGRAPHICS, PSYCHOSOCIAL WELL-BEING, AND HEALTH-RELATED HINDRANCE OF ADOLESCENTS WITH AND WITHOUT CANCER

Variable	Cancer group (n = 102)	Healthy group (n = 97)	p
Gender (male), n (%)	58 (57)	51 (53)	0.54
Age, M (SD; range = 13–19)	15.75 (1.76)	15.55 (1.74)	0.42
Minority status (minority), n (%)	33 (32)	40 (41)	0.19
Income ^a (lower income), n (%)	29 (31)	10 (11)	0.001
Overall HRQOL, M (SD; range = 0–100)	61.34 (17.78)	78.83 (11.36)	<0.001
Depression, M (SD; range = 0–100)	46.08 (6.57)	46.19 (6.76)	0.91
Negative affect, M (SD; range = 10–50)	21.40 (8.6)	20.44 (6.81)	0.38
Positive affect, M (SD; range = 10–50)	30.03 (8.77)	34.55 (7.21)	<0.001
HRH scales, M (SD; range = 0–6)			
Total HRH	2.77 (1.47)	0.89 (0.89)	<0.001
Pain HRH	2.57 (1.56)	0.87 (1.04)	<0.001
Fatigue HRH	2.94 (1.58)	1.58 (1.35)	<0.001
Other symptoms HRH	2.67 (1.59)	0.58 (0.87)	<0.001
Health self-management HRH	2.89 (1.64)	0.52 (0.98)	<0.001

Note: Italicized *p*-values are statistically significant.

Ranges in the left column represent possible range for that measure.

^aIncome was not used as a covariate in final analyses given: (1) eight participants did not report on income and (2) results did not change with including income as a covariate.

HRH, health-related hindrance; HRQOL, health-related quality of life.

Correlations (for continuous variables) and *t*-tests (for dichotomous variables) tested associations between HRH and demographic variables in the full sample and cancer group to identify covariates for analysis.

We tested whether adolescents with and without cancer differed on HRH by regressing HRH on disease status (cancer or healthy), controlling for demographic covariates. To examine the extent of the problem of HRH for adolescents with cancer, we performed four linear regressions entering HRH as a predictor of HRQOL, depression, negative affect, and positive affect, controlling for demographic covariates. Next, we conducted correlations (for continuous variables), *t*-tests (for dichotomous variables), and F-tests (for categorical variables) to assess the relationships of HRH with disease-related and psychosocial variables. Associates of HRH were entered into a regression predicting HRH, with demographic covariates, disease-related factors, and psychosocial factors entered in separate blocks. Because multiple measures of pain were examined in bivariate tests, only pain severity was used as a predictor in multivariate models to avoid multicollinearity problems and because it has been identified as most highly predictive of most health-related outcomes.⁴⁶

During the study design phase, sample size was determined by power analyses generated using previous comparable data.¹⁷ Power analyses indicated that a sample size of 69 adolescents with cancer and 69 healthy peers was required to test group differences on HRH after adjusting for potential confounders (e.g., age, gender) with 80% power to detect effects at an alpha threshold of 0.008. For analyses with the cancer group, power analyses indicated that a minimum of 96 participants were needed to test a multiple linear regression model with up to six covariates ($R^2 = 0.15$) to detect effects at an alpha value of 0.008 with 80% power. Thus, the current group sizes (102 participants with cancer and 97 healthy peers) were adequate to conduct the current analyses.

Results

Participants

Of 133 potential participants with cancer, 123 provided consent/assent and 102 completed the study. Reasons for not participating included parent refusal ($n=4$), too burdensome ($n=2$), too sick ($n=1$), cognitive limitations ($n=1$), or no reason provided ($n=2$). Of 128 potential control participants who were screened, 114 were eligible and agreed to participate, and 97 completed the study. There were no significant demographic differences between those who agreed and refused to participate, and those did and did not complete the study. Almost all variables of the demographics and self-report measures had normally distributed residuals and no extreme cases in the full sample or cancer-only group. Perceived life threat was zero-inflated and was dichotomized (0 = none, 1 = any perceived life threat). Among those with cancer, girls reported more HRH than boys [$t(100) = -2.24$, $p = 0.03$]; therefore, sex was included as a covariate in regression analyses in the cancer group. Descriptives of the groups are in Tables 1 and 2.

HRH among adolescents with cancer: comparison to healthy peers and associated outcomes

On average, adolescents with cancer scored 1.88 points higher on HRH than healthy adolescents ($b = 1.88$, $SE = 1.7$,

TABLE 2. DISEASE, TREATMENT, AND PSYCHOSOCIAL VARIABLES AMONG ADOLESCENTS WITH CANCER ($N = 102$)

<i>Disease-related variables</i>	<i>Descriptives</i>
Diagnosis, <i>n</i> (%)	
Leukemia	30 (29)
Lymphoma	20 (20)
Brain tumor	11 (11)
Solid tumor	41 (40)
Months since diagnosis, <i>M</i> (SD)	20.44 (38.59; 1–193)
Relapsed (yes), <i>n</i> (%)	28 (28)
Number of days inpatient, <i>M</i> (SD)	37.94 (38.85; 0–200)
Treatment intensity, <i>n</i> (%)	
Moderate	21 (21)
Very	45 (44)
Most	36 (35)
Perceived life threat (yes), <i>n</i> (%)	20 (20)
Pain severity in past 4 weeks, <i>M</i> (SD; range = 0–5)	2.38 (1.35)
Pain frequency in past 4 weeks, <i>M</i> (SD; range = 0–5)	2.45 (1.45)
Current pain, <i>M</i> (SD; range = 0–10)	2.25 (2.86)
Pain HRQOL, <i>M</i> (SD; range = 0–100)	58.70 (28.84)
Fatigue HRQOL, <i>M</i> (SD; range = 0–100)	55.88 (22.83)
Nausea HRQOL, <i>M</i> (SD; range = 0–100)	56.03 (23.17)
Cognitive problems HRQOL, <i>M</i> (SD; range = 0–100)	67.84 (22.00)
Stress-processing factors	
Positive reframing, <i>M</i> (SD; range = 2–8)	5.45 (1.66)
Active coping, <i>M</i> (SD; range = 2–8)	5.44 (1.49)
Intrapersonal factors	
Self-efficacy, <i>M</i> (SD; range = 20–100)	69.68 (11.97)
Dispositional hope, <i>M</i> (SD; range = 1–6)	4.31 (1.05)
Social-ecological factors	
Family functioning, <i>M</i> (SD; range = 1–4)	
Patient report	1.87 (0.43)
Caregiver report	1.79 (0.47)
Family support, <i>M</i> (SD; range = 0–20)	15.18 (4.39)
Peer support, <i>M</i> (SD; range = 0–20)	15.00 (4.04)

Percentages may not add up to 100% because of missing data or participants who endorsed multiple options. Ranges reported in the variable (leftmost) column are the range of response options for that measure.

$\beta = 0.61$, $p < 0.001$; $R^2 = 0.37$; Table 1), with scores approaching midrange of moderate HRH. Controlling for sex, adolescents with cancer who reported greater HRH had significantly worse HRQOL ($p < 0.001$), more negative affect ($p = 0.03$), and higher depression scores ($p = 0.03$), but there was not an association with positive affect (Table 3).

Disease-related and psychosocial associates of HRH among adolescents with cancer

Worse fatigue, nausea, cognitive problems, and pain-related HRQOL, and more current and past month pain severity and frequency were associated with greater total HRH (Table 4). Higher caregiver-reported family functioning was marginally associated with lower HRH.

We conducted a hierarchical regression predicting HRH from associates entered in the following steps: sex (step 1); fatigue, nausea, cognitive problems, and past month pain

TABLE 3. LINEAR REGRESSIONS PREDICTING PSYCHOSOCIAL OUTCOMES FROM HRH AMONG ADOLESCENTS WITH CANCER

Predictors	HRQOL			Depression			Negative affect			Positive affect		
	b (SE)	β	p	b (SE)	β	p	b (SE)	β	p	b (SE)	β	p
Sex	-1.92 (3.33)	-0.05	<i><0.001</i>	-0.01 (1.33)	0.00	0.99	1.34 (1.72)	0.08	0.44	0.16 (1.82)	0.01	0.93
Total HRH	-4.96 (1.12)	-0.41	<i><0.001</i>	0.98 (0.45)	0.22	0.03	1.26 (0.58)	0.22	0.03	-0.13 (0.61)	-0.02	0.84

Note: Italicized *p*-values are statistically significant.

Male is the reference group for the sex variable. Unstandardized (*b*) and standardized (β) regression coefficients are reported. The standard error (SE) reported is the standard error of the unstandardized regression coefficient. $R^2=0.18$ for model predicting HRQOL; $R^2=0.05$ for model predicting Depression; $R^2=2.06$ for model predicting Negative affect, and $R^2=0.00$ for model predicting Positive affect.

TABLE 4. DISEASE-RELATED AND PSYCHOSOCIAL FACTORS ASSOCIATED WITH HRH IN ADOLESCENTS WITH CANCER

Disease-related factors	r with HRH	p
Months since diagnosis	0.00	0.98
Number of days inpatient	0.00	0.99
Pain severity (past 4 weeks)	0.52	<i><0.001</i>
Pain frequency (past 4 weeks)	0.49	<i><0.001</i>
Current pain	0.38	<i><0.001</i>
Pain HRQOL ^a	-0.42	<i><0.001</i>
Fatigue HRQOL ^a	-0.49	<i><0.001</i>
Nausea HRQOL ^a	-0.31	0.002
Cognitive problems HRQOL ^a	-0.20	0.04
Mean comparisons		
M (SD)		
Relapsed	<i>t</i> =0.09	0.93
No (<i>n</i> =73)	2.77 (1.53)	
Yes (<i>n</i> =28)	2.74 (1.33)	
Perceived life threat	<i>t</i> =-0.27	0.79
No (<i>n</i> =81)	2.76 (1.44)	
Yes (<i>n</i> =20)	2.86 (1.64)	
Treatment intensity	<i>F</i> =0.13	0.88
Moderate (<i>n</i> =21)	2.78 (1.54)	
Very (<i>n</i> =45)	2.69 (1.55)	
Most (<i>n</i> =36)	2.86 (1.36)	
Stress processing approaches	r with HRH	
Positive reframing	0.14	0.16
Active coping	0.02	0.88
Intrapersonal factors	r with HRH	
Self-efficacy	0.01	0.91
Dispositional hope	0.01	0.95
Social-ecological factors	r with HRH	
Family functioning ^b		
Patient report	0.05	0.65
Caregiver report	0.18	0.07
Family support	0.11	0.29
Peer support	0.11	0.27

Note: Italicized *p*-values are statistically significant.

The pattern of bivariate relationships between examined variables and HRH was similar across subscales of HRH. This indicates that the specific type of HRH is not as important as the perceived impact of any symptoms on goal pursuit. Correlation coefficients were computed using bivariate Pearson correlations. *t*-Tests were conducted to compare means on binary variables, and ANOVA was conducted to yield an omnibus *F*-statistic to compare means of categorical variables.

^aHigher scores correspond to better HRQOL (i.e., fewer problems).

^bHigher scores correspond to worse family functioning.

severity (step 2; disease-related risk factors); and caregiver-reported family functioning (step 3; psychosocial resilience factor) (Table 5). The following variables related to HRH once all variables were entered into the final step: female gender ($p=0.03$), more severe pain ($p<0.001$), and greater caregiver-reported family functioning ($p=0.01$). Worse fatigue HRQOL was marginally associated with more HRH ($p=0.09$). Because of the prominence of pain as a predictor, we analyzed how many adolescents endorsed any pain (in addition to average ratings reported in Table 2); 93% provided a pain severity rating above "0" in the last 4 weeks and 68% endorsed some current pain.

Discussion

The current study measured the impact of cancer treatment and physical symptoms on goal pursuit of adolescents with cancer by assessing HRH—a novel and developmentally

TABLE 5. LINEAR REGRESSION PREDICTING HRH FROM SIGNIFICANT ASSOCIATES AMONG ADOLESCENTS WITH CANCER

Predictors	b (SE)	β	p
Step 1: Demographic covariates			
Sex	0.65 (0.29)	0.22	0.03
Step 2: Disease-related variables			
Sex	0.44 (0.25)	0.15	0.08
Pain severity (last 4 weeks)	0.36 (0.11)	0.33	<i>0.001</i>
Fatigue HRQOL	-0.02 (0.01)	-0.25	0.03
Nausea HRQOL	-0.01 (0.01)	-0.10	0.27
Cognitive problems HRQOL	-0.00 (0.01)	-0.01	0.87
Step 3: Psychosocial factors			
Sex	0.52 (0.24)	0.18	0.03
Pain severity	0.42 (0.11)	0.39	<i><0.001</i>
Fatigue HRQOL	-0.01 (0.01)	-0.19	0.09
Nausea HRQOL	-0.01 (0.01)	-0.13	0.14
Cognitive problems HRQOL	0.00 (0.01)	0.02	0.83
Caregiver-reported family functioning	0.72 (0.26)	0.23	0.01

Note: Italicized *p*-values are statistically significant.

Male is the reference group for the sex variable. Unstandardized (*b*) and standardized (β) betas are reported. Step 1 $\Delta R^2=0.05$, $p=0.03$; Step 2 $\Delta R^2=0.31$, $p<0.001$; Step 3 $\Delta R^2=0.05$, $p=0.01$; and Total $R^2=0.41$.

sensitive approach to understanding adolescent adjustment to cancer. The focus on adolescents and their goals directly responds to calls to better understand the unique experience of this understudied population.^{21,22} The study was strengthened by inclusion of a control group, a sample of more than one-third racial/ethnic minorities, and use of the disability-stress-coping model²⁸ to theoretically inform choices of assessed predictor variables. Overall, results support that HRH is a problem for adolescents with cancer, especially those who are female, with pain, and with low family functioning and, to some extent, those with fatigue.

As expected, adolescents with cancer experienced more HRH than healthy peers. Among adolescents with cancer, HRH was associated with poor outcomes, including worse HRQOL and more depressive symptoms and negative affect. While the literature reports varied findings on HRQOL and other measures of well-being among youth with cancer, patients may be more likely to feel negatively impacted by cancer if it is negatively affecting personal goals. Prior research suggests that adolescents with cancer report similar goals as their healthy peers across multiple domains.¹⁹ Yet, they have relatively poorer developmental outcomes or take longer to reach young adult developmental milestones compared with healthy peers and siblings.^{18,24} Considering the current findings in light of prior research, HRH among adolescents with cancer may be an early warning sign for impaired well-being in adolescence and developmental difficulties later in young adulthood.

Physical symptoms of nausea, fatigue, pain, and cognitive problems related to HRH. It is understandable that symptoms such as feeling ill or unfocused would hinder the ability to pursue goals. Similarly, a large cohort study of adolescents and young adults with cancer (AYA HOPE) found that 34% of participants reported one or two symptoms, 23% reported three or four, and 28% reported more than five symptoms; physical symptoms were the strongest predictor of HRQOL.⁴⁷ Pain emerged as a significant predictor of HRH in the current study, which is not surprising given that almost the entire sample endorsed some pain. Fatigue emerged as marginally significant. Our results, combined with those from the AYA HOPE study⁴⁷ and other studies identifying pain management as an unmet need,²⁰ provide further support for the need to address adolescents' pain and other physical sequelae of cancer and its treatment.

Caregiver-reported family functioning was the only resilience factor associated with HRH. While coping styles, self-efficacy, optimism, and family factors are theoretically associated with goal pursuit among adolescents,⁴⁸ these characteristics may not be strong enough to overcome the impact of cancer and its sequelae on HRH. On the contrary, adolescents from healthier functioning families may fair better because their family better manages the impact of cancer symptoms on the adolescents' day-to-day life or is better able to support the adolescent's goal pursuit.⁴⁹

There are a few limitations of this article and future directions worth mentioning. While we measured HRH in a decent sized sample to sufficiently power regression analysis, we were not powered to test more detailed models or interactions predicting HRH. We also did not measure HRH over time; HRH may change with fluctuating symptoms, changing treatment, time stage of the cancer trajectory, and adjustment to cancer. Although pain emerged as a significant predictor,

details about the pain (origin, type, location) are not known and should be explored in future studies. In addition, although we included healthy adolescents as a comparison group, we did not conduct a case-controlled study through which control cases would be matched to patients with cancer. We also did not have another chronic illness comparison group. Thus, we are unable to conclude whether findings are specific to adolescents with cancer, or if they generalize across chronic illnesses. A prior article found consistent findings in a sample of survivors of pediatric cancer, youth with cystic fibrosis, and never ill adolescents.¹⁷ The current study extends these findings into youth undergoing active treatment for cancer. The finding of female sex related to HRH also warrants further study, but is consistent with studies demonstrating worse HRQOL among female AYA with or who survived cancer.^{50,51}

Results identify modifiable targets of intervention to address unmet needs of adolescents with cancer—an underserved population in need of new approaches for supportive care.^{21,22} There is a need to attend to and develop more effective guidelines for treating physical symptoms, particularly pain management.⁴ Reducing pain and other symptoms may result in less HRH, ultimately minimizing derailment from or slowing down of normative developmental trajectories. Enhancing or sustaining family functioning is also an important intervention target. Family-based interventions have been effective in pediatric oncology and can be modified to address the unique needs and challenges faced by families with an adolescent with cancer.^{52,53} Finally, HRH itself may be a target of intervention by (1) increasing support for goal pursuit and (2) helping adolescents differentiate between realistic and nonrealistic goals in the face of cancer, while modifying or choosing alternative valued goals. Repeated assessment of HRH can track the impact of cancer on changing goals, guiding the precision of intervention and symptom management. Furthermore, HRH can be compared between adolescents and young adults or used to examine impact of cancer on goals as adolescents transition into emerging adulthood and adjust their goals in response to new developmental tasks.^{16,54} For example, as adolescents transition into emerging adulthood, HRH of job/occupational goals may increase as the salience of job/occupational goals increases. Overall, reducing HRH and supporting goal achievement have important implications for development, well-being, and successful transition to adulthood, and can minimize the impact of cancer on adolescents.

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