

Psychological Outcomes and Health Beliefs in Adolescent and Young Adult Survivors of Childhood Cancer and Controls

Anne E. Kazak, Branlyn Werba DeRosa, Lisa A. Schwartz, Wendy Hobbie, Claire Carlson, Richard F. Ittenbach, Jun J. Mao, and Jill P. Ginsberg

From the Division of Oncology, Children's Hospital of Philadelphia; Department of Pediatrics, University of Pennsylvania School of Medicine; and Department of Family Medicine, The University of Pennsylvania Health System, Philadelphia, PA.

Submitted August 31, 2009; accepted January 4, 2010; published online ahead of print at www.jco.org on March 15, 2010.

Supported by Grant No. CA106928 from the National Cancer Institute.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Anne E. Kazak, PhD, ABPP, Division of Oncology, Children's Hospital of Philadelphia, Room 1486 CHOP North, 34th St and Civic Center Blvd, Philadelphia, PA, 19104; e-mail: kazak@email.chop.edu.

© 2010 by American Society of Clinical Oncology

0732-183X/10/2812-2002/\$20.00

DOI: 10.1200/JCO.2009.25.9564

A B S T R A C T

Purpose

The purpose of this study was to compare adolescent and young adult (AYA) pediatric cancer survivors and peers without a history of serious illness on psychological distress, health-related quality of life (HRQOL), health beliefs; examine age at diagnosis and cancer treatment intensity on these outcomes; and examine relationships between number of health problems and the outcomes.

Patients and Methods

AYA cancer survivors ($n = 167$) and controls ($n = 170$), recruited during visits to a cancer survivorship clinic and primary care, completed self-report questionnaires of distress, health problems, and health beliefs. For survivors, providers rated treatment intensity and health problems.

Results

There were no statistically significant differences between survivors and controls in psychological distress or HRQOL. Cancer survivors had less positive health beliefs. Survivors diagnosed as adolescents had significantly greater psychological distress and fewer positive health beliefs than those diagnosed earlier. Survivors with the highest level of treatment intensity had greater anxiety and fewer positive health beliefs than those with less intense treatments. Provider report of current health problems related to survivors' beliefs and mental HRQOL only, whereas patient report of health problems correlated significantly with most psychosocial outcomes and beliefs.

Conclusion

AYA cancer survivors did not differ from peers in psychological adjustment but did endorse less adaptive health beliefs. Survivors diagnosed during adolescence and who had more intensive cancer treatments evidenced poorer psychosocial outcomes. Beliefs about health may be identified and targeted for intervention to improve quality of life, particularly when patient perceptions of current health problems are considered.

J Clin Oncol 28:2002-2007. © 2010 by American Society of Clinical Oncology

INTRODUCTION

Long-term survivors of pediatric cancer demonstrate resilience in long-term adjustment and quality of life.¹ However, subgroups are at risk for poor outcomes^{2,3} and approximately 10% to 20% score in the clinical range on psychological measures.⁴⁻⁷ Adolescent and young adult (AYA) survivors are underinvestigated and may be particularly vulnerable, medically and psychosocially.^{1,4,5,8-10} In general, AYAs engage in riskier health behaviors and are less likely to utilize health care than other age groups.¹¹ For AYA survivors in particular, vulnerability may be related to late effects of cancer treatment and the transition of health care responsibilities inherent in young adulthood.¹² Evidence of the difficulty in educating and engaging survivors in their disease self-

management comes from the Childhood Cancer Survivor Study where only 35% of survivors recognize that they could have serious health problems related to their cancer treatment¹³ and more than 50% do not receive cancer-related follow-up care.¹⁴ The psychosocial sequelae of AYA survivors are important as they may relate to successful management of late effects and adherence to treatment recommendations during these transitions.²

Despite the importance of understanding AYA well-being, few studies have focused on this specific age group, especially among those seeking medical care. Thus, providers have little knowledge of how the adjustment of the AYA survivors they follow differs from other generally healthy AYAs who are in a doctor's office seeking care. Previous literature has been limited by a focus on psychological symptoms

(eg, anxiety, depression, post-traumatic stress) or generic quality of life measures that may not be optimal, in isolation, for understanding and improving well-being, especially among AYAs.¹⁵ In an instrument development article, we identified four types of health-related beliefs and a 21-item measure—the Health Competence Beliefs Inventory (HCBI). AYA cancer survivors reported fewer adaptive beliefs related to health perceptions, cognition, and autonomy but more positive beliefs about satisfaction with health care (DeRosa et al, submitted for publication).

Previous literature has also not clarified potential disease-related risk factors for poor outcomes during the AYA period. One variable that is readily available to providers and may relate to psychosocial risk for survivors is age at cancer diagnosis. Little is known about how age at diagnosis impacts long-term adjustment. Treatment of adolescent cancers can be longer and more challenging than that of children, and there are unique developmental and psychosocial aspects of adolescence that impact care.¹⁰ Cancer-related disruptions (eg, hospitalizations, medical appointments, procedures, adverse effects) of critical developmental processes (eg, autonomy, interpersonal relationships, cognitive maturation) may cause psychological distress into adulthood. AYA survivors who were diagnosed in adolescence typically have health-related quality of life (HRQOL) issues that are different, and often more significant, than those diagnosed before adolescence.¹⁷⁻¹⁹

Current health problems and treatment intensity may also relate to psychosocial outcomes. Late effects typically increase during adolescence and young adulthood and providers shift communication from parents to their patients^{11,20} in anticipation for the transition to adult care. Morbidity related to health problems and/or the awareness of potential risk are likely related to adjustment.^{2,21} Higher treatment intensity is also likely to relate to psychological distress for AYAs due to increasing cognitive abilities to remember and understand the implications treatment and because of the higher likelihood of medical morbidities.²

There are three aims in this study. The first is to compare psychosocial outcomes (distress, HRQOL, and beliefs about health and well-being) of AYA long-term pediatric cancer survivors and peers without a history of serious health problems within the context of a medical visit. The second aim is to examine if the outcomes differ among cancer survivors by their age at diagnosis and intensity of cancer treatment. The third aim estimates the strength and directionality of the relationships between number of health problems and the aforementioned outcomes for survivors, using both self and provider reports.

PATIENTS AND METHODS

Participants

AYA participants ($n = 337$), ranged in age from 16 to 30 years (mean, 20.5 years; standard deviation, 3.2 years). For survivors ($n = 167$), eligibility criteria included a diagnosis of cancer before age 21 years, at least 5 years from cancer diagnosis (long-term survivor), English speaking, and able to read independently at the fifth grade level. Survivors were diagnosed from birth to 20 years (mean, 8.4 years; standard deviation, 5.3 years). Exclusion criteria were brain tumor diagnosis and/or severe cognitive impairment. Control group participants ($n = 170$) met the following eligibility criteria: no history of life-threatening or chronic illness or injury (eg, diabetes, severe asthma), English-speaking, able to read independently at the fifth grade level. Controls

with a psychiatric hospitalization or current pregnancy were excluded due to complex medical needs. Among cancer survivors, specific diagnoses were leukemia (44.9%), lymphoma (19.8%), and solid tumor (35.3%). Reasons for the primary care visit for the control participants were routine visit (47.1%), minor acute illness (27.1%), follow-up visit (18.2%), or not specified (7.6%).

Procedures

Participants were recruited from March 2006 through August 2009 in this institutional review board–approved study. The data were collected at or immediately after a medical appointment. Survivors ($n = 167$) were recruited during annual visits to a pediatric cancer survivorship clinic. The control group ($n = 170$) was recruited from an urban family practice office ($n = 119$), a suburban adolescent medicine practice ($n = 34$), and a university student health center ($n = 17$). Control group recruitment was targeted to the age, sex, and race/ethnicity of the survivor population. Eligible patients were approached in the waiting room by a research assistant who described the study and completed informed consent. Of the 462 participants approached, 81% consented ($n = 376$). Of those who consented, 89% completed study measures (73% of all those originally approached). Participants received \$20 for study completion.

Measures

A demographic form assessed age, sex, ethnicity/race, education, income, and household composition. Control group participants recorded the reason for their visit (eg, routine, follow-up, acute problem). The six scales used are described below. All participants completed the measures of psychological distress and HRQOL and health beliefs. The groups differed in terms of the data collected on health status and treatment history.

Psychological Distress and HRQOL

The Brief Symptom Inventory 18 (BSI-18)²² is an 18-item standardized self-report symptom inventory of psychological distress and a Global Severity Index, which yields three subscales (depression, anxiety, and somatic symptoms) with demonstrated reliability and validity. The Post-Traumatic Stress Checklist-Civilian version (PCL-C)²³ is a valid 17-item self-report questionnaire of DSM-IV symptoms of post-traumatic stress disorder (PTSD). The PCL-C yields three subscales, representing symptom clusters of the DSM-IV PTSD criteria (re-experiencing, avoidance, arousal). The Short-Form Health Status questionnaire (SF-12)²⁴ is a standardized 12-item measure of HRQOL with two empirically derived subscales: physical and mental HRQOL.

Health Beliefs

The Health Competence Beliefs Inventory (HCBI; DeRosa et al, submitted for publication) is a 21-item multidimensional scale, developed in this study, as a measure of beliefs about health and well-being. There is a total score and four factors: health perceptions (eg, I'm not as healthy as other people my age), satisfaction with health care (eg, my doctor understands my concerns), cognitive competence (eg, I learn things as easily as other people), and autonomy (eg, I feel comfortable going to the doctor by myself), all of which exhibit good reliability (range, 0.75 to 0.87). Validation of the factors supports predicted associations with distress, HRQOL, and provider-reported health problems.¹⁶

Health Status and Treatment History

There are parallel patient and provider versions of The Health Knowledge Inventory (HKI),²⁵ a 35-item checklist developed in this study to assess current health problems. The HKI lists problems (with examples) that can apply to both survivors and controls (eg, heart/blood problems: weak heart, chest pain, irregular heartbeat, high blood pressure). Problems may be organic/major (ie, related to major organ system and/or a significant late effect of childhood cancer) or constitutional/other (ie, a problem related to the whole system, and therefore, may not be specific [eg, fatigue] or may be a less medically significant and threatening problem [eg, taste or hearing problems]). Patients endorse (yes/no) whether they have each resulting in a total score. Providers complete the same form for their patients.

For cancer survivors, diagnosis, stage, and treatment modality (eg, radiation, chemotherapy, surgery, stem cell transplantation) was extracted via chart review to calculate treatment intensity using the four levels of the Intensity of Treatment Rating scale 2.0 (ITR-2).²⁶ Rater reliability in prior studies is excellent,^{26,27} as well as in the current sample $r_s = 0.96$.

Statistical Analysis

The study had two phases. In the first, descriptive phase traditional measures of central tendency and variability were computed for all relevant variables and comparisons made between the groups (ie, cancer survivors, controls), to better understand the comparability of the samples. In the second, inferential phase comparisons were made between cancer survivors and control samples (aim 1), then across age of diagnosis categories (ie, early childhood, school age, adolescence), treatment intensity categories (least/moderate, very intense, most intense), and number of health problems (aim 2). For aims 1 and 2, comparisons were conducted for psychological outcomes, HRQOL, and health beliefs, using one-way analyses of variance and follow-up Tukey least significant differences pair-wise tests, as appropriate. Age at diagnosis was extracted from medical records and treated as a categorical variable (eg, birth through 5 years, 6 to 12 years, and 13 or older). Relationships between number of medical problems on the HKI and outcome variables were estimated and tested using Spearman rho (r_s) correlation coefficients (aim 3). Statistical significance was evaluated at the nominal $\alpha = .05$ level, without adjustment for multiple comparisons. All data were analyzed using SPSS version 16 (SPSS Inc, Chicago, IL).

RESULTS

Demographic Comparability and Differences Between AYA Cancer Survivors and Controls (aim 1)

There were no differences between AYA cancer survivors and controls on age, sex, ethnicity, education, or income (Table 1).

The cancer survivors had less competent health beliefs (HCBI) overall, and scored lower on three of the four indices of health competence beliefs: health perceptions, cognitive competence, and autonomy (Table 2). Survivors scored significantly higher (more competent beliefs) in satisfaction with health care. The groups did not differ significantly in distress (BSI), post-traumatic stress (PCL-C), or HRQOL (SF-12).

Age at Diagnosis (aim 2)

Post-traumatic stress, HRQOL, and health competence beliefs differed by age at diagnosis (Table 3). Survivors diagnosed as adolescents had significantly more total PTSD symptoms and re-experiencing symptoms than those diagnosed at school age. They also reported more arousal symptoms than both other age groups. Similarly, survivors diagnosed as adolescents had significantly lower psychosocial HRQOL than those diagnosed in school age, and significantly lower health perceptions and cognitive competence than those diagnosed earlier. There were no statistically significant differences by age at diagnosis for general distress or physical HRQOL. We also examined whether this finding could be related to the length of time from diagnosis. As would be expected given the sample's age range, age at diagnosis was significantly inversely related to length of time since diagnosis ($r = -0.75$; $P = .000$). However, length of time since diagnosis was not related to any of the outcome variables.

Treatment Intensity (aim 2)

Patients with the most intense treatments had more anxiety and avoidance, and less overall health competence, health perceptions, and cognitive competence than those with less intense treatment (Table 4). Psychological distress or HRQOL did not differ significantly by levels of treatment intensity on the ITR-2.

Table 1. Demographic and Disease Characteristics

Characteristic	Survivors (n = 167)		Controls (n = 170)		P
	Frequency	%	Frequency	%	
Mean age, years	20.2		21.8		.12
Standard deviation	3.2		3.2		
Female sex	88	53	87	51	.78
Ethnicity/race					.16
African-American	8	5	20	12	
Asian	5	3	6	4	
White	148	89	135	79	
Hispanic	4	2	5	3	
More than one race	2	1	4	2	
Education					.24
< high school graduate	47	28	33	20	
High school graduate	25	15	41	24	
Some college	60	36	47	28	
Graduated college	35	21	47	28	
Annual family income, \$.19
< 35,000	21	14	38	25	
35,000-74,999	50	33	49	32	
75,000-124,999	57	38	35	23	
> 125,000	22	15	32	21	
Intensity of treatment					
Least	5	4			
Moderately	72	44			
Very	57	36			
Most intense	26	16			
Cancer diagnosis					
Leukemia	75	45			
Lymphoma	33	20			
Solid tissue	59	35			
Age at diagnosis, years					
Early childhood (≤ 5)	67	41			
School (6-12)	58	35			
Adolescent (≥ 13)	39	24			

NOTE. t -tests were conducted for continuous variables (age), χ^2 analyses for categorical variables (eg, sex, ethnicity), and Kendall's tau-b for ordinal variables (eg, family income, education).

Number of Health Problems (aim 3)

The number of current provider-reported health problems did not correlate with measures of psychosocial outcomes, but was significantly inversely related to mental HRQOL, total health competence beliefs, and two subtype of beliefs (health perceptions and cognitive competence; Table 5). In contrast, patient-reported health problems were associated with all psychosocial outcomes, HRQOL, and total health competence beliefs, as well as three subtypes of those beliefs (health perceptions, satisfaction with health care, and cognitive competence; Table 5).

DISCUSSION

Consistent with prior research on psychological adjustment in pediatric cancer survivors,^{1,2} AYA pediatric cancer survivors attending a cancer survivorship clinic did not differ from AYA patients in a primary care setting without a history of serious illness on psychological distress or HRQOL. Despite the potential for increased anxiety and/or decreased HRQOL at the time of a medical appointment, the scores

Table 2. Psychological Outcomes, HRQOL, and Health Competence Beliefs: AYA Cancer Survivors and Controls

Outcome	Survivors (n = 167)		Controls (n = 170)		F	P
	Mean	SD	Mean	SD		
General distress (BSI GSI)	52.14	9.22	51.01	9.63	1.17	.28
Depression	52.56	9.22	51.98	9.27	0.33	.56
Anxiety	49.94	9.45	49.46	9.37	0.22	.64
Somatic	51.52	8.97	50.59	9.55	0.83	.36
Post-traumatic stress (PCL-C)	26.35	10.03	26.15	10.00	0.03	.86
Re-experiencing	7.60	3.63	7.34	3.41	0.44	.51
Avoidance	10.31	4.04	10.16	4.40	0.10	.75
Arousal	8.49	3.60	8.64	3.35	0.17	.68
HRQOL (SF-12)						
Physical	48.77	4.74	47.97	5.57	1.91	.17
Psychosocial	44.60	5.35	44.70	6.16	0.02	.89
Health competence beliefs						
Total score	64.68 (7.58)	7.78	69.83	7.28	37.32	.00
Health perceptions	18.14	4.01	20.64	3.29	38.30	.00
Satisfaction with health care	17.26	2.41	16.59	2.54	6.07	.01
Cognitive competence	15.25	2.85	15.89	2.71	4.38	.04
Autonomy	14.08	2.92	16.42	2.82	54.95	.00

NOTE. Higher scores for SF-12 and Health Competence Beliefs Inventory are more adaptive. On the PCL-C and BSI higher scores indicate more symptoms. All scores on the psychological outcome measures are within normal limits. Abbreviations: AYA, adolescent and young adult; SD, standard deviation; BSI GSI, Brief Symptom Inventory Global Severity Index; PCL-C, Post-Traumatic Stress Checklist-Civilian version; HRQOL, health-related quality of life; SF-12, Short-Form Health Status questionnaire.

Table 3. Age at Cancer Diagnosis and Outcome Measures

Outcome Measure	Age at Diagnosis						P
	Early Childhood (n = 67)		School Age (n = 58)		Adolescence (n = 39)		
	Mean	SD	Mean	SD	Mean	SD	
General distress (BSI GSI)	52.1	9.8	50.7	9.2	53.8	8.1	.27
Depression	52.2	9.3	51.5	9.0	54.2	9.2	.35
Anxiety	49.5	10.0	48.3	9.0	52.4	8.9	.11
Somatization	52.0	9.8	50.6	8.7	51.8	8.3	.64
Post-traumatic stress (PCL-C)*	26.2	10.0	24.2	7.5	29.9	12.7	.03
Re-experiencing*	7.7	3.8	6.7	2.2	8.8	4.7	.02
Avoidance	10.3	3.8	9.5	3.4	11.5	5.1	.06
Arousal†	8.1	3.6	8.0	2.9	9.7	4.3	.04
HRQOL (SF-12)							
Physical QOL	48.3	5.4	49.3	3.8	48.7	4.8	.50
Mental QOL‡	45.9	5.2	44.5	4.7	42.5	5.9	.01
Health beliefs (HCBI)	65.2	7.7	65.4	7.1	63.0	8.9	.27
Health perceptions†	18.8	4.0	18.4	4.0	16.7	3.9	.03
Satisfaction with health care	17.1	2.4	17.4	2.5	17.4	2.4	.80
Cognitive competence†	15.5	2.6	15.7	2.5	14.3	3.5	.04
Autonomy	13.8	3.0	14.1	3.0	14.5	2.8	.43

NOTE. Higher scores for SF-12 and HCBI are more adaptive. On the PCL-C and BSI higher scores indicate more symptoms. Abbreviations: SD, standard deviation; BSI GSI, Brief Symptom Inventory Global Severity Index; PCL-C, Post-Traumatic Stress Checklist-Civilian version; HRQOL, health-related quality of life; SF-12, Short-Form Health Status questionnaire; HCBI, Health Competence Beliefs Inventory. *Adolescents significantly different from school age, $P < .05$. †Adolescents significantly different from the other two age groups, $P < .05$. ‡Adolescents significantly different from early childhood, $P < .05$.

for both groups of patients were within normal limits. The consistency of this finding across differing populations and methodologies reinforces the finding of relatively good psychological health and resilience of pediatric cancer survivors. It also underscores the importance of moving the field beyond simple group differences (ie, survivors, controls) in psychological adjustment to identify potential risk factors and approaches that providers of survivorship care could integrate in clinically.

One such approach is health competence beliefs; AYA survivors seeking health care have less competent beliefs than AYA peers in a medical setting. In other words, there are meaningful differences among survivors and controls on how they perceive their health and health care. Such beliefs offer an alternative means of understanding survivors' experiences and reactions that could be explored in terms of their relationship to health behaviors,²⁸ and as potential modifiable targets of intervention. For example, the belief "My future health is very uncertain" may relate to distress (ie, anxiety, depression) and certain health behaviors (eg, hypervigilance about health or avoidance of health care). Providers can explore such malleable beliefs in a nonthreatening way. Using approaches consistent with cognitive behavioral therapy, maladaptive beliefs leading to distress and poor disease self-management can be modified.²⁹ Assessing health competence beliefs in survivorship care settings and developing brief interventions to help AYA survivors and their families develop and use more adaptive beliefs are next steps of this work.

Specifically, AYA cancer survivors had significantly more positive beliefs about satisfaction with the health care team in general (eg, My doctors understand my medical history) than controls. Acknowledg-

ing that this sample is biased toward cancer survivors who are attending a survivorship clinic who may be more adherent to treatment recommendations in general and may have particularly complex medical issues,³⁰ the data nonetheless address the importance of engaging survivors in long-term care and working with them to develop the skills necessary to navigate the health care system over time. AYA cancer survivors' beliefs reflect their perceived bad luck and uncertainty about their health, including concerns about future medical problems (ie, health perceptions) and beliefs (ie, cognitive competence) that they have cognitive challenges that could impact their function (eg, memory, attention, intellect). They similarly endorse beliefs that underscore their reliance on their families (eg, spending most free time with their parents/siblings) at higher levels than controls.

Adolescence is a time of transition and vulnerability. Long-term survivors diagnosed and treated during adolescence had higher levels of post-traumatic stress, including arousal and re-experiencing, and lower HRQOL than those diagnosed at younger ages. This finding is novel, complex, and potentially discrepant from prior research,⁴ necessitating further attention to this age group. In this study, patients diagnosed during adolescence also reported beliefs that are less positive, particularly in relation to their health perceptions and cognitive capabilities. These data support the vulnerability of youth diagnosed during adolescence and the critical need for focused attention to their longer term developmental course as they grow into young adulthood.

Table 4. Treatment Intensity and Outcome Measures

Outcome Measure	Treatment Intensity						P
	Least/ Moderately Intense (n = 77)		Very Intense (n = 58)		Most Intense (n = 26)		
	Mean	SD	Mean	SD	Mean	SD	
General distress (BSI GSI)	52.2	9.8	50.5	8.4	54.7	9.8	.15
Depression	52.6	9.2	50.9	8.8	55.7	10.3	.09
Anxiety*	50.8	9.4	47.3	7.9	52.3	12.0	.04
Somatization	51.6	9.5	51.1	8.7	51.7	9.0	.94
Post-traumatic stress (PCL-C)	26.5	9.3	24.7	9.2	30.2	13.7	.08
Re-experiencing	7.7	3.3	6.9	3.1	8.9	5.3	.07
Avoidance†	10.3	3.8	9.6	3.5	12.0	5.6	.04
Arousal	8.4	3.6	8.3	3.7	9.2	3.7	.59
HRQOL (SF-12)							
Physical QOL	48.7	5.0	48.5	4.0	49.0	5.7	.91
Mental QOL	44.5	5.3	45.3	4.9	43.4	6.1	.31
Health beliefs (HCBI)‡	65.7	8.2	65.4	7.1	60.8	7.5	.02
Health perceptions‡	18.9	4.3	18.2	3.5	16.2	3.7	.01
Satisfaction with health care	17.1	2.6	17.5	2.2	17.4	2.5	.61
Cognitive competence‡	15.6	2.8	15.5	2.6	13.8	3.2	.02
Autonomy	14.2	2.9	14.2	2.8	13.3	3.2	.40

NOTE. Higher scores for SF-12 and HCBI are more adaptive. On the PCL-C and BSI, higher scores indicate more symptoms. The two least intense categories on the ITR-2 (least, moderately severe) were combined due to the small number of patients in these groups.

Abbreviations: SD, standard deviation; BSI GSI, Brief Symptom Inventory Global Severity Index; PCL-C, Post-Traumatic Stress Checklist-Civilian version; HRQOL, health-related quality of life; SF-12, Short-Form Health Status questionnaire; HCBI, Health Competence Beliefs Inventory.

*Most intense and least/moderately intense significantly different from very intense, $P < .05$.

†Most intense significantly different from very intense, $P < .05$.

‡Most intense significantly different from least/moderately intense and very intense, $P < .05$.

Understanding how the intensity of treatment and ongoing health concerns may influence adjustment remains underinvestigated. Although objective treatment-related variables are often not associated with psychological outcomes,⁴ these data support the risk of both psychological difficulties and fewer adaptive beliefs among those patients with the most intensive cancer treatments. It may be that, at the highest levels of intensity, there is less variability in how both patients and providers view this construct as well as the impact on their lives. The data on number of health problems highlights the potential discrepancy between the number of problems identified by providers versus those identified by the patients, in terms of psychological outcomes and beliefs. Provider reports of the number of current health problems were associated with patients' health beliefs, but not other measures of psychological outcome. This suggests that more health problems may have greater impact on health beliefs, perhaps reflecting a realistic acceptance of current health problems in this population. In contrast, survivors' report of the number of their health problems was more consistently and strongly associated with overall psychological well-being. This may reflect a more global appraisal of how poorer perceived health may impact well-being.

Table 5. Current Health Problems (provider/patient report) Correlated With Psychological Outcomes, HRQOL, Health Competence Beliefs, and Treatment Intensity

Parameter	No. of Current Health Problems			
	Provider Report		Patient Report	
	r	P	r	P
Psychological outcome				
General distress (BSI GSI)	0.08	.35	0.46	.00
Depression	-0.01	.90	0.33	.00
Anxiety	0.04	.67	0.43	.00
Somization	0.17	.04	0.44	.00
Post-traumatic stress (PCL-C)	0.11	.19	0.46	.00
Re-experiencing	0.07	.38	0.31	.00
Avoidance	0.11	.19	0.43	.00
Arousal	0.13	.12	0.48	.00
HRQOL (SF-12)				
Physical	-0.04	.65	-0.33	.00
Mental	-0.19	.03	-0.23	.01
Health beliefs (HCBI)				
HCBI total	-0.29	.0	-0.44	.00
Health perceptions	-0.38	.0	-0.52	.00
Satisfaction health care	-0.04	.66	-0.09	.25
Cognitive competence	-0.18	.03	-0.39	.00
Autonomy	-0.06	.49	0.03	.74

Abbreviations: BSI GSI, Brief Symptom Inventory Global Severity Index; PCL-C, Post-Traumatic Stress Checklist-Civilian version; HRQOL, health-related quality of life; SF-12, Short-Form Health Status questionnaire; HCBI, Health Competence Beliefs Inventory.

There are both strengths and limitations in this research. The AYA cancer survivors are from one data collection, one institution, and may not reflect patients seen in other settings. While a population-based methodology provides advantages in identifying broad patterns of association among variables, our more in-depth methodology provides information useful to clinicians in their interactions with patients. The sample is mostly non-Hispanic white. While this is consistent with the general childhood cancer survivorship population and the Childhood Cancer Survivor Study,³¹ it remains a limitation in the broader survivorship field, particularly because beliefs may be influenced by culture. Finally, the control group is an innovative and important one. We recognize that AYAs seeking health care may be more worried or preoccupied about their health than the general population. This could mask some differences between controls and survivors. On balance, however, this control group provides a rather unique, clinically relevant comparison and contrast for survivors in clinical care. By recruiting age-matched peers, our methodology has a significant advantage over studies that use sibling controls. Siblings cannot be considered independent observations; siblings are affected by pediatric cancer and demonstrate a range of psychosocial outcomes linked to the serious illness in the family.³²

In conclusion, the results of this study support the psychological well-being of AYA cancer survivors in the context of a survivorship clinic visit while also highlighting the importance of understanding beliefs specific to health and well-being in this population. Higher-risk groups within this population include those diagnosed during adolescence and those with the highest levels of treatment intensity. Thus, while most survivors are psychologically resilient, disease-related variables readily known to care providers can help to identify the significant minority of those at risk for difficulties with psychosocial

functioning and less competent health beliefs. Identifying and providing interventions to this minority group of AYA patients is critical for facilitating optimal transition to adulthood and adult-oriented care.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Anne E. Kazak, Branlyn Werba DeRosa, Lisa A. Schwartz, Wendy Hobbie, Richard F. Ittenbach, Jill P. Ginsberg

Administrative support: Anne E. Kazak

Provision of study materials or patients: Anne E. Kazak, Wendy Hobbie, Jun J. Mao, Jill P. Ginsberg

Collection and assembly of data: Anne E. Kazak, Branlyn Werba DeRosa, Lisa A. Schwartz, Wendy Hobbie, Claire Carlson, Jun J. Mao, Jill P. Ginsberg

Data analysis and interpretation: Anne E. Kazak, Branlyn Werba DeRosa, Lisa A. Schwartz, Wendy Hobbie, Claire Carlson, Richard F. Ittenbach, Jun J. Mao, Jill P. Ginsberg

Manuscript writing: Anne E. Kazak, Branlyn Werba DeRosa, Lisa A. Schwartz, Wendy Hobbie, Claire Carlson, Richard F. Ittenbach, Jun J. Mao, Jill P. Ginsberg

Final approval of manuscript: Anne E. Kazak, Branlyn Werba DeRosa, Lisa A. Schwartz, Wendy Hobbie, Claire Carlson, Richard F. Ittenbach, Jun J. Mao, Jill P. Ginsberg

REFERENCES

1. Zebrack BJ, Chesler, MA: Quality of life in childhood cancer survivors. *Psychooncology* 11:132-141, 2002
2. Zeltzer LK, Recklits CJ, Buchbinder D, et al: Psychological status in childhood cancer survivors: A report for the childhood cancer survivor study. *J Clin Oncol* 27:2396-2404, 2009
3. Gurney JG, Krull KR, Kadan-Lottick N, et al: Social outcomes in the childhood cancer survivor study cohort. *J Clin Oncol* 27:2390-2395, 2009
4. Rourke MT, Hobbie WL, Schwartz LA, et al: Posttraumatic stress disorder (PTSD) in young adult survivors of childhood cancer. *Pediatr Blood Cancer* 49:177-182, 2007
5. Schwartz L, Drotar D: Posttraumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *J Pediatr Psychol* 31:356-366, 2006
6. Brown RT, Madan-Swain A, Lambert R: Post-traumatic stress symptoms in adolescent survivors of childhood cancer and their mothers. *J Trauma Stress* 16:309-318, 2003
7. Hobbie WL, Stuber M, Meeske K, et al: Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *J Clin Oncol* 18:4060-4066, 2000
8. National Cancer Institute, LIVESTRONG Young Adult Alliance: Closing the gap: Research and care imperative for adolescents and young adults with cancer, report of the adolescent and young adult oncology progress review group. National Institutes of Health Publication No. 06-6067, 2006
9. Stam H, Hartman EE, Deurloo JA, et al: Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *J Adolesc Health* 39:4-13, 2006
10. Bleyer WA: Cancer in older adolescents and young adults: Epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol* 38:1-10, 2002
11. Park MJ, Mulye TP, Adams SH, et al: The health status of young adults in the U.S. *J Adolesc Health* 39:305-317, 2006
12. Oeffinger KC, Mertens AC, Hudson MM, et al: Health care of young adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Ann Fam Med* 2:61-70, 2004
13. Kadan-Lottick NS, Robison LL, Gurney JG, et al: Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood cancer survivor study. *JAMA* 287:1832-1839, 2002
14. Nathan PC, Greenberg ML, Ness KK, et al: Medical care in long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *J Clin Oncol* 26:4401-4409, 2008
15. Zebrack B: Developing a new instrument to assess the impact of cancer in young adult survivors of childhood cancer. *J Cancer Surviv* 3:174-180, 2009
16. Reference deleted
17. Barrera M, Wayland L, D'Agostino NM, et al: Developmental differences in psychological adjustment and health-related quality of life in pediatric cancer patients. *Child Health Care* 32:215-232, 2003
18. Felder-Puig R, Formann AK, Mildner A, et al: Quality of life and psychosocial adjustment of young patients after treatment of bone cancer. *Cancer* 83:69-75, 1998
19. Grant J, Cranston A, Horsman J, et al: Health status and health-related quality of life in adolescent survivors of cancer in childhood. *J Adolesc Health* 38:504-510, 2006
20. Ginsberg JP, Hobbie WL, Carlson CA, et al: Delivering long-term follow-up care to pediatric cancer survivors: Transitional care issues. *Pediatr Blood Cancer* 46:169-173, 2006
21. Schwartz L, Werba B, Carlson C, et al: Measurement and correlates of health outcomes of childhood cancer survivors. Presented at Regional Child Health Psychology Conference, Cincinnati, OH, April 26-28, 2007
22. Derogatis LR: Brief Symptom Inventory (BSI). Minneapolis, MN, NCS Pearson Inc, 2000
23. Weathers FW, Ford J: Psychometric review of the PTSD Checklist, in Stamm BH (ed): *Measurement of Stress, Trauma, and Adaptation*. Lutherville, MD, Sidran Press, 1996, pp 250-251
24. Ware JE Jr, Kosinski M, Keller SD: A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* 34:220-233, 1996
25. Schwartz LA, Mao JJ, Werba BE, et al: Self-reported health problems of young adults in clinical settings: Survivors of childhood cancer and healthy controls. *J Am Board Fam Med* (in press)
26. Werba BE, Hobbie W, Kazak AE, et al: Classifying the intensity of pediatric cancer treatment protocols: The intensity of treatment rating scale 2.0 (ITR-2). *Pediatr Blood Cancer* 48:673-677, 2007
27. Pai AL, Patino-Fernandez AM, McSherry M, et al: The psychosocial assessment tool (PAT2.0): Psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *J Pediatr Psychol* 33:50-62, 2008
28. Haller D, Sanci Lena, Sawyer S, et al: Do young people's illness beliefs affect health care? A systematic view. *J Adolescent Health* 42:436-449, 2008
29. Kazak A, Alderfer M, Streisand R, et al: Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: A randomized clinical trial. *J Fam Psychol* 18:493-504, 2004
30. Ness KK, Leisenring W, Goodman P: Assessment of selection bias in clinic-based populations of childhood cancer survivors: A report from the childhood cancer survivor study. *Pediatr Blood Can* 52:379-386, 2008
31. Robison LL, Mertens AC, Boice JD, et al: Study design and cohort characteristics of the Childhood Cancer Survivor Study: A multi-institutional collaborative project. *Med Pediatr Oncol* 38:229-239, 2002
32. Alderfer MA, Long KA, Lown EA, et al: Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psychooncology* [epub ahead of print on October 27, 2009]