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Predictors of future health-related quality of life in survivors of adolescent cancer

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Abstract

The purpose of this study was to identify characteristics associated with health-related quality of life (HRQOL) among long-term survivors of adolescent cancer enrolled in the Childhood Cancer Survivor Study. Thirty percent of survivors reported poor physical and/or mental HRQOL. Race/ethnicity, education, and head/neck disfigurement were significantly associated with poor mental HRQOL, while sex, age, household income, obesity, alkylating agents, pelvic radiation, head/neck or limb disfigurement, and walking with a limp were associated with poor physical HRQOL. Identification of high-risk adolescent cancer patients may facilitate timely intervention to attempt to minimize the impact of cancer and treatment on subsequent quality of life.

Keywords

Adolescent cancer survivor; Quality of life

Introduction

The 5-year survival rate for all pediatric cancers combined is now 80%.[1] As these rates increase and more patients survive into adulthood, it is important to understand both how the cancer experience impacts future quality of life, and to know who is most at risk for poor quality of life.

Adolescence is characterized by physiological, cognitive and behavioral changes[2] that contribute to increased concern with body-image, and to the desire to transition from the dependence of childhood to the independence of adulthood.[2] Adolescents often have

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difficulty in situations where they perceive a lack of control.[3] The experience surrounding cancer diagnosis and treatment is a situation that may be viewed as the ultimate loss of control and may result in increased anxiety and emotional distress. In this report, we describe factors associated with poor HRQOL among those diagnosed as adolescents. We hypothesize that, in addition to sociodemographic characteristics, disfigurement is associated with an increased risk of reporting poor HRQOL.

Patients and Methods

Participants for this study were selected from the Childhood Cancer Survivor Study (CCSS),[4,5,6] limited to those diagnosed from ages 10 to 18 years, who participated in the psycho-social portion of the 2003 Follow-Up survey and who consented to medical record abstraction. Those diagnosed with a second malignant neoplasm before the 2003 Follow-Up survey were excluded so as to study only those characteristics related to the adolescent cancer experience.

Our primary outcome of interest was self-reported health-related quality of life (HRQOL), defined by the Medical Outcomes Short Form-36 (SF-36). T-scores were determined for the two summary scales, physical and mental HRQOL, dichotomized at one standard deviation (SD = 10) below the general population mean (mean=50). Participants with a t-score ≤ 40 were considered to have poor HRQOL. Candidate predictors of HRQOL included baseline demographics including sex, race/ethnicity, household income and education, body mass index (BMI), self-reported disfigurement and treatment related variables such as surgery, chemotherapy, and radiation.

Descriptive statistics including frequencies, means and standard deviations, medians and ranges were calculated. Multivariable logistic regression models were generated for each outcome, poor physical and mental HRQOL, using backward selection methods to identify significant predictors. Variables with a p value of <0.1 were retained in the final model. All analyses were done using SAS software version 9.3 (SAS Institute, Cary, NC).

Results

Characteristics of the study population are shown in table 1. Of the 2,064 survivors, 49% were female and 92% were White, non-Hispanic. 44% had a college degree, with 25% having a household income ≥ $60,000. Mean (SD) age at diagnosis was 13.8 (2.4) years. The majority were diagnosed with leukemia or lymphoma (65%) and treated with radiotherapy (66%). Some form of disfigurement was reported by 67% of the sample.

Race/ethnicity and disfigurement were significantly associated with poor mental HRQOL, with non-white survivors of adolescent cancer and those with disfigurement of the head/neck being more likely to report poor mental HRQOL (table 2). Female sex, older current age, low household income (<$20,000), obesity, exposure to alkylating agents, radiation to the pelvis, walking with a limp and disfigurement of the head/neck or limbs were all significantly associated with poor physical HRQOL. Relative to a high school education, a college education was associated with decreased reporting of both poor mental and physical HRQOL.

Discussion

This study sought to identify factors associated with poor physical and mental HRQOL among adult survivors of adolescent cancer. This work builds on a previous CCSS study that found those diagnosed between 10 and 20 years of age had the highest risk of poor physical HRQOL.[7] Physical susceptibility, combined with diagnosis and treatment during a particularly turbulent emotional developmental stage, suggests that this subgroup of survivors may be at high risk for poor HRQOL and therefore warranted further study.

This study identified race/ethnicity and disfigurement as associated with poor mental HRQOL, and sex, education, household income, disfigurement, current age, obesity, and exposure to alkylating agents and/or radiation to the pelvis as associated with poor physical HRQOL. The results of this study are in agreement with previous studies among pediatric cancer survivors that found minority status[8] and disfigurement of the head/neck and limb[9] was associated with poor mental health outcomes. Additionally, when considering the broader age range for survivors of childhood and adolescent cancer, previous studies have identified obesity,[10] female sex,[7,11–13] educational attainment[7,14], household income,[7,14] increased age,[14] disfigurement[9] and pelvic irradiation[14] as predictors of poor HRQOL.

It is not entirely surprising to find disfigurement to be so strongly associated with poor physical and mental HRQOL in survivors diagnosed during adolescence. Adolescence is the stage during which a sense of identity is formed.[15] Psychologists Erikson[16] and Seltzer[17] assert that peer-group membership is necessary to healthy identity development since it allows the adolescent to decrease psychological dependence on their parents, yet retain a sense of belonging.[18] A cancer diagnosis, its treatment, and its related sequelae may threaten peer-group membership, by denying the adolescent opportunity for membership physically, because s/he is undergoing treatment and therefore not able to attend school or social events, or emotionally because of perceived differences between the adolescent cancer patient and his/her “normal” peers. Limited interaction with peers may lead to a distorted sense of identity, and combined with physical deformity, likely affects adult HRQOL.

The results of this study suggest two possible types of interventions. To address the emotional reaction to head/neck disfigurement, increased social support and enhanced self-efficacy would be advised.[19] Cognitive behavioral therapy has been demonstrated an effective therapeutic approach for this purpose.[20] Related to poor physical HRQOL, results would suggest targeting a weight loss program, as obesity is the only modifiable risk factor. Given that higher education was associated with better mental and physical HRQOL, an educational intervention may also be explored as a route of enhancing adjustment to late-effects of cancer survivorship.

It is important to interpret these results keeping in mind the following limitations. First, our outcome was obtained by self-report. Second, this is a fairly young cohort of survivors with 90% of participants younger than age 45 at evaluation of HRQOL. It is possible that some late effects of treatment have not yet occurred, and we are therefore underestimating the true prevalence of poor physical HRQOL. Additionally, some participants may be too young to

have experienced fertility issues, employment difficulties, difficulties obtaining health insurance, etc.; all of which may contribute to poor mental HRQOL.

This report identifies characteristics that may help identify childhood cancer survivors at the highest risk for reporting HRQOL. Early identification of these patients will allow clinicians to connect survivors of adolescent cancer with the appropriate resources and interventions in a timely manner, perhaps minimizing the impact of cancer and its treatment on the adolescent survivors' future quality of life.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Characteristics of study population

	Survivors n (%)(n = 2003)	Poor Mental HRQOL n (%)(n = 343)	Poor Physical HRQOL n (%)(n = 360)
Sex			
Male	1050 (52)	161 (47)	161 (45)
Female	953 (48)	182 (53)	199 (55)
Race/Ethnicity			
White, non-Hispanic	1837 (92)	309 (90)	323 (90)
Black, non-Hispanic	58 (3)	9 (3)	11 (3)
Hispanic	54 (3)	9 (3)	16 (4)
Other	48 (2)	15 (4)	8 (2)
Unknown	6 (<1)	1 (<1)	2 (1)
Education			
Less than high school	100 (5)	26 (8)	34 (9)
High School	263 (13)	52 (15)	66 (18)
Some College	649 (32)	114 (33)	112 (31)
Bachelor's degree or greater	895 (45)	132 (38)	121 (34)
Missing/ Unknown	96 (5)	19 (6)	27 (8)
Household Income			
<$20,000	326 (17)	75 (24)	93 (28)
$20,000 to <$40,000	575 (29)	108 (31)	105 (29)
$40,000 to <$60,000	446 (22)	60 (18)	62 (17)
Over $60,000	518 (26)	72 (21)	75 (21)
Missing/Unknown	138 (5)	28 (8)	29 (8)
Marital Status			
Never married	707 (35)	125 (36)	104 (29)
Married	1096 (55)	178 (51)	210 (58)
No longer married	156 (8)	34 (9)	36 (10)
Missing/Unknown	44 (2)	13 (4)	10 (3)
Age at cancer diagnosis (years)			
Mean (SD)	13.7 ± 2.4	14.0 ± 2.3	13.5 ± 2.3
10 to 14	1228 (61)	223 (65)	206 (57)
15 to 18	775 (39)	120 (35)	154 (43)
Age at SF-36			
Mean (SD)			
Range	37.2 ± 5.0	38.2 ± 5.3	36.8 ± 5.1
25 to 34	666 (33)	125 (36)	95 (26)
35 to 44	1175 (59)	193 (56)	218 (61)
45 +	160 (8)	25 (7)	46 (13)
BMI			
<18	84 (4)	17 (5)	21 (6)
18 to 24	1076 (54)	192 (56)	163 (45)

	Survivors n (%)(n = 2003)	Poor Mental HRQOL n (%)(n = 343)	Poor Physical HRQOL n (%)(n = 360)
25 to 30	574 (29)	88 (26)	96 (27)
30 +	239 (12)	41 (12)	75 (21)
Missing/Unknown	30 (2)	5 (1)	5 (1)
Cancer diagnosis			
Leukemia	421 (21)	63 (18)	56 (16)
Central nervous system	281 (14)	62 (18)	54 (15)
Hodgkin disease	446 (22)	79 (20)	80 (22)
Non-Hodgkin lymphoma	223 (11)	39 (11)	29 (8)
Wilms tumor	19 (1)	3 (1)	-
Neuroblastoma	5 (<1)	-	-
Soft tissue sarcoma	225 (11)	36 (11)	39 (11)
Bone cancer	383 (19)	71 (21)	100 (28)
Treatment exposure			
Surgery			
Lower limb amputation	197 (10)	31 (9)	57 (16)
Other amputation/ unspecified limb	37 (2)	9 (3)	7 (2)
None	1685 (87)	289 (84)	278 (77)
Missing/Unknown	84 (4)	14 (4)	18 (5)
Chemotherapy			
Anthracyclines	899 (45)	146 (43)	167 (46)
Alkylating agent	1163 (58)	197 (57)	222 (62)
Platinum	139 (7)	32 (9)	28 (8)
Bleomycin	225 (11)	36 (11)	43 (12)
Epipodophyllotoxins	118 (6)	19 (6)	23 (6)
Site of Radiation Exposure			
Brain	518 (26)	88 (26)	84 (23)
Chest	526 (26)	88 (26)	93 (26)
Other head	137 (7)	19 (6)	21 (6)
Neck	495 (25)	85 (25)	85 (24)
Abdomen	340 (17)	48 (14)	69 (19)
Spine	136 (7)	16 (5)	27 (8)
Pelvis	278 (14)	41 (12)	60 (17)
Limb	140 (7)	16 (5)	26 (7)
TBI	30 (2)	2 (1)	4 (1)
Any	1309 (65)	220 (64)	232 (65)
Disfigurement			
Hair loss	269 (13)	56 (16)	57 (16)
Scarring of head or neck	456 (23)	111 (32)	94 (26)
Scarring of chest or abdomen	642 (32)	117 (34)	133 (37)
Scarring of arms or legs	451 (23)	86 (25)	118 (33)
Walk with a limp	310 (15)	53 (15)	109 (30)

Data are presented as n (%) or mean ± standard deviation. Abbreviations: SF-36 – Medical Outcomes Short Form-36; BMI – Body Mass Index; TBI – Total body irradiation.

Table II

Predictors of poor mental HRQOL and poor physical HRQOL

	Poor Mental HRQOL OR (95% CI)	Poor Physical HRQOL OR (95% CI)
Sex		
Male		1.00
Female		1.74 (1.31, 2.30)
Race/Ethnicity		
White, non-Hispanic	1.00	
Black, non-Hispanic	0.90 (0.43, 1.87)	
Hispanic	1.03 (0.48, 2.27)	
Other	2.51 (1.30, 4.82)	
Education		
Less than high school	1.22 (0.69, 2.16)	1.51 (0.84, 2.71)
High School	1.00	1.00
Some college	0.83 (0.57, 1.20)	0.60 (0.40, 0.89)
Bachelor's degree or greater	0.67 (0.47, 0.97)	0.55 (0.37, 0.82)
Household Income		
$10,000 to <$20,000		1.90 (1.26, 2.86)
$20,000 to <$40,000		1.05 (0.72, 1.53)
$40,000 to <$60,000		0.89 (0.59,1.37)
Over $60,000		1.00
Age at SF-36		
25 to 34		1.0
35 to 44		1.33 (0.96, 1.83)
45 +		2.26 (1.37, 3.70)
BMI		
<18		1.37 (0.98, 2.15)
18 to 24		1.0
25 to 30		1.20 (0.87, 1.67)
30 +		2.60 (1.77, 3.83)
Treatment		
Alkylating agent		1.37 (1.03, 1.83)
Radiation to pelvis		1.63 (1.13, 2.35)
Disfigurement		
Scarring of head or neck	1.84 (1.41, 2.41)	1.37 (0.99, 1.90)
Scarring of arms or legs	1.25 (0.95, 1.66)	1.45 (1.06, 1.98)
Walk with a limp		3.26 (2.33, 4.56)

Abbreviations: OR (95% CI) – Odds Ratio and 95% Confidence interval. SF-36 – Medical Outcomes Short Form-36; BMI – Body Mass Index.