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Health Related Quality of Life, Lifestyle Behaviors, and Intervention Preferences of Survivors of Childhood Cancer

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Abstract

PURPOSE—Childhood cancer survivors (CCSs) are at increased risk for poor health-related quality of life (HRQOL) and chronic health conditions -- both of which can be exacerbated by unhealthy lifestyle behaviors. Developing a clearer understanding of the associations between HRQOL, lifestyle behaviors, and medical and demographic variables (e.g., age/developmental stage at time of diagnosis) is an important step toward developing more targeted behavioral interventions for this population.

METHOD—Cross-sectional questionnaires were completed by 170 CCSs who were diagnosed with leukemia, lymphoma, sarcoma, or a cancer of the central nervous system (CNS) and treated at a comprehensive cancer center between 1992 and 2007. Questionnaires addressed weight status, lifestyle behaviors, aspects of HRQOL, and intervention preferences.

RESULTS—Adolescent and young adult survivors (AYAs) and survivors of CNS tumors or lymphoma reported significantly ($p < .05$) poorer HRQOL across multiple domains compared to those diagnosed at an earlier age, survivors of leukemia or sarcoma, and healthy populations. A significant proportion also failed to meet national recommendations for dietary intakes (39–94%) and physical activity (65%). Female survivors reported poorer physical functioning and consumed less dietary fiber and fruits and vegetables than did male survivors. They also expressed the strongest interest in participating in diet and exercise interventions.

CONCLUSION—Findings support the premise that females, AYAs, and survivors of cancers of the CNS or lymphoma are “at risk” subgroups within the CCS population for poor dietary practices, sedentary behaviors, and poor HRQOL. Future research should focus on developing diet and PA interventions to improve HRQOL that target these groups.

IMPLICATIONS FOR SURVIVORS—Greater consideration of the role of gender, developmental stage, and the HRQOL challenges facing CCSs may help researchers to develop targeted behavioral interventions for those who stand to benefit the most.

Keywords

childhood cancer; diet; physical activity; health related quality of life; intervention preferences

INTRODUCTION

Forty years ago, the mortality rate for childhood cancers was over 50% [1]. Today, thanks to major advances in treatment, 80% of children who are diagnosed with cancer will survive five years or more [1]. Despite this success, childhood cancer survivors (CCSs) face a wide variety of medical complications as a result of their disease and its treatment. For example, when compared to age and gender matched peers, CCSs are at increased risk for developing diabetes, cardiovascular disease, and second malignancies later in life, as well as experiencing deficits in health-related quality of life (HRQOL) [2–5]. The late effects experienced by CCSs contribute to disabilities that threaten their ability to function normally and live independently.

Engaging in recommended amounts of physical activity (PA) and consuming a lower-fat diet that is high in fruits and vegetables (F&V) and whole grains may shield survivors from some of these late effects [3; 6–9]; however, many CCSs fail to adhere to national diet and PA recommendations. For example, Demark-Wahnefried and colleagues [10] observed that more than one-third of adolescent and adult survivors of childhood cancers were obese and few met the guidelines for PA and a healthy diet. Robien and colleagues [11] found that 55% of CCSs met requirements for F&Vs (5 servings/day) and fat (35% of calories) intake but that 90% failed to consume adequate amounts of fiber. Although some CCSs practice healthy lifestyle habits that mirror those of “healthy” peers [12–14], the levels may be considered suboptimal due to their increased risk of developing metabolic syndrome and other health problems compared to the general population [15; 16]. Thus, empirically-based diet and exercise interventions that address the unique needs of this growing and vulnerable population are warranted. Unfortunately, the few studies that have examined diet and exercise behaviors among CCSs have focused on specific cancer subtypes (e.g., acute lymphoblastic leukemia) [10; 17], making it difficult to make comparisons across diagnoses. Indeed, more research is needed on the diet and PA of a broader range of survivors, including those who were treated for lymphoma, sarcoma, and tumors of the CNS, because these individuals are particularly vulnerable to metabolic syndrome (e.g., insulin resistance or obesity) due to the nature of their disease and its treatment [15; 16].

Studies in cancer have shown that targeted interventions are generally more effective than “one size fits all” behavior change programs [for a review, see 18]. This may be particularly true for CCSs, who are a heterogeneous group – particularly with regard to non-modifiable group-level characteristics such as cancer diagnosis, age or developmental stage at time of diagnosis, and sex [19; 20]. Thus, in an effort to develop more targeted interventions for CCSs, it may be useful to examine associations between these group-level characteristics and lifestyle behaviors such as diet and PA. It may also be useful to examine associations between weight status/lifestyle behaviors and more modifiable characteristics such as HRQOL that may be adversely affected by childhood cancer and its treatment.

Despite the fact that HRQOL is a multidimensional construct that includes both general and disease-specific factors, studies have largely focused on associations between general HRQOL and lifestyle behaviors in adult cancer survivors [21–23]. However, as more studies are published regarding the late effects experienced by CCSs, it is becoming increasingly apparent that this population of cancer survivors report significantly lower levels of physical, mental, and social and emotional functioning than age- and gender-matched peers

[24; 25]. Moreover, establishing a relationship between specific aspects of HRQOL and lifestyle behaviors/weight status is a preliminary step to the creation of lifestyle behavioral interventions designed to improve HRQOL and ameliorate the adverse effects of cancer and its treatment. For example, survivors with greater pain and fatigue may be reluctant or unable to be physically active and more likely to have a high body mass index (BMI); these survivors may require adaptive intervention approaches that take such side-effects into consideration. Finally, theories such as the health belief model [26] and theory of planned behavior [27] which are commonly used to explain the uptake of health behaviors specify that one's perception of vulnerability to a health threat is an important influence on the practice of protective health behaviors. From this perspective, it may be useful to examine associations between weight status/lifestyle behaviors and aspects of HRQOL such as cancer worry or concerns about bodily appearance. Indeed, survivors who worry more about developing recurrent or new cancer or who are more concerned than other survivors about their bodily appearance after treatment may be more motivated to eat a healthy diet and engage in PA and thus be more receptive to making lifestyle behavioral changes and participating in diet and exercise programs [28; 29].

As the above review shows, more research is needed to understand the lifestyle behaviors of CCSs as well as the modifiable and non-modifiable factors that may affect their pursuit of healthier lifestyles. Thus, the goals of our study were to: 1) characterize the relationship between weight status (as body mass index; BMI) and lifestyle behaviors (i.e., diet and PA) among CCSs and determine whether differences in weight status and lifestyle behaviors exist depending on group-level characteristics (e.g., age/developmental stage, gender, cancer type); 2) determine whether differences in HRQOL exist depending on group-level characteristics and lifestyle behaviors (e.g., whether or not CCSs are meeting national guidelines for diet and PA); and, 3) characterize the intervention preferences of CCSs and determine whether these preferences differ on the basis of group-level characteristics and HRQOL. Although our goals were largely exploratory, consistent with previous studies [22; 30–34] we expected that weight status, diet (i.e., F&V consumption, fiber intake, percent of energy from fat), and PA would be significantly associated with each other. We further hypothesized that group-level characteristics such as male gender, younger age, and having a diagnosis of CNS cancer or leukemia would be associated with engaging in more healthy lifestyle behaviors and that CCSs who practiced healthy lifestyle behaviors (i.e., adhered to national guidelines for BMI, diet, and PA) would report better HRQOL.

PROCEDURE

This study was approved by The University of Texas MD Anderson Cancer Center Institutional Review Board. Survivors were identified from the Children's Cancer Hospital database and were eligible if they (1) had been diagnosed with leukemia, lymphoma, sarcoma, or cancer of the CNS between 1992 and 2007, (2) were 18 years or younger at the time of diagnosis, (3) had concluded active treatment at least 6 months previously with no evidence of progressive disease, and (4) were able to read and understand English.

Although 505 CCSs were identified as being potentially eligible to participate, further examination revealed that eight were deceased and 215 had addresses that could not be verified (e.g., they moved and did not notify the hospital of their forwarding address). Thus, a total of 282 packets containing a cover letter describing the study, the study questionnaire, a \$5 gift card incentive, and a postage-paid envelope were mailed to eligible survivors whose addresses could be verified. Up to three reminder telephone calls were made to encourage individuals to return surveys. Similar methods for tracing, contacting, and recruiting survivors have been reported elsewhere [35]. Because of the detailed recall required by some of the measures and the young age of some of the survivors in our sample,

parents of children < 12 years old were allowed to assist their children in completing the surveys. Signed consent was obtained for adult survivors and the parents/guardians who assisted with survey completion for children who were younger than 12 years old; child assent was obtained for minor-aged survivors. Survivors were asked to self-report if they received assistance in completing their surveys, by answering the question, “Did your parent help you fill out this survey (yes/no)?”. Parents who assisted with survey completion were also instructed to indicate their assistance.

Measures

Questionnaires consisted largely of validated measures that assessed HRQOL, BMI, dietary intake, PA, and willingness to participate in diet and PA interventions. Demographic (e.g., age at time of study entry) and medical variables (e.g., cancer diagnosis, length of time since treatment) were also assessed. Regardless of their age at time of study entry, participants were classified as either child (originally diagnosed with cancer between the ages of 0 and 14) or adolescent and young adult (AYA) survivors (originally diagnosed with cancer between the ages of 15 and 29).¹ We chose to assess developmental stage at time of cancer diagnosis in this way based on National Cancer Institute (NCI) and Centers for Disease Control (CDC) definitions and because research suggests that the long-term side effects of childhood cancer may vary according to the developmental stage of the child at time of diagnosis and treatment [36–38].

HRQOL—We measured HRQOL by using select subscales from the Pediatric Quality of Life (PedsQL 4.0) instrument [39; 40]. Specifically, we used the physical function subscale from the generic core (8-items), general (6 items) and cognitive fatigue (6 items) subscales from the multidimensional fatigue core, and the cognitive function (5 items), pain and hurt (2-items), worry (3 items) and body appearance (3 items) subscales from the cancer core. One of the advantages of the PedsQL is that it provides norms for each of these subscales, allowing for comparisons with the general healthy population [41]. The PedsQL has demonstrated reliability and validity among survivors of childhood cancer [1] and has been validated in both child [42] and young adult populations [43].

To facilitate subscale comparisons across age groups, items were modified to be conceptually similar across all age groups in our sample while using developmentally appropriate language. For example, one item on the cognitive function subscale was changed for adult CCSs by omitting the word ‘school’ from the following item: “I have trouble writing (school) papers or reports.” Similar modifications for age have been reported elsewhere [44; 45]. Each subscale was ranked on a 5-point Likert response scale from 0 (never a problem) to 4 (always a problem). Summative scores were computed by reverse scoring and transforming each item to a scale of 0 to 100 (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicated better quality of life. To account for missing data, we calculated scores as the sum of the items divided by the number of items answered. If > 50% of the items in the scale were missing, the scale score was not computed. Internal consistency coefficients for our various subscales ranged from $\alpha = .66$ – $.89$ depending on age group/developmental stage. Small to moderate correlations were observed among our subscales indicating discriminate validity.

BMI—BMI (kg/m^2) was computed from self-reported height and weight. Adolescent and child survivors were categorized as underweight (<5th percentile), normal weight (5th to

¹The NCI and CDC definition for an AYA survivor is having received a diagnosis of cancer between the ages 15 and 29; however, given the eligibility criteria in the current study, all the AYA cancer survivors in our sample were diagnosed between the ages of 15 and 18.

<85th percentile), or overweight or obese (≥85th percentile) based on guidelines established by the CDC [46]. Adult survivors (≥21 years old at the time of the study) of childhood cancer were categorized as underweight (BMI<18.5), normal weight (BMI 18.5–24.9), or overweight or obese (BMI≥24.9) based on established clinical guidelines [47].

Dietary Intakes—The 17-item National Cancer Institute Multifactor Screener was used to provide general estimates of F&V intake, percent of calories from fat, and grams of fiber over a 12-month period by using established algorithms [48]. Because the survey was mailed, the use of dietary recalls or lengthy food frequency questionnaires was not possible. However, the Multifactor Screener has been shown to provide reasonable estimates for F&V, fat, and fiber intakes [48]. Age- and gender-specific cutoffs were used to determine whether participants were meeting national guidelines [49–52]. Respondents who consumed at least 5 servings of F&Vs and obtained <35% of their energy from fat met current recommendations. Fiber adequacy was calculated in terms of grams consumed as a function of assumed age-appropriate energy intakes, and we used cut points recommended by the Food and Nutrition Board of the National Institute of Medicine [53].

PA—The Godin Leisure-Time Exercise Questionnaire [GLTEQ; 54; 55] elicits information regarding the frequency of strenuous, moderate, and mild PA that lasts > 15 minutes per session and then converts this information to PA metabolic equivalents (METs). Because time (minutes) spent engaging in moderate and strenuous PA is associated with amount of health benefit [56], we focused only on these levels of PA. First, we calculated the Godin leisure time activity (LTA) score, which corresponds to MET values for moderate and vigorous activity, by weighting and summing the frequencies of these behaviors (5x moderate + 9x strenuous) [56]. LTA scores were then multiplied by 4 to calculate participants' total MET minutes for the week [57]. The reliability of the GLTEQ has been independently evaluated and found to compare favorably to nine other measures of self-report exercise, objective monitors, and fitness indices [58]. To determine whether respondents were meeting current guidelines for PA, an additional item was adapted from the Youth Risk Behavior Survey: “During the past 7 days, on how many days were you physically active for at least 30 [for adults]/60 [for children and adolescents] minutes per day?” [59].

Receptivity to Participating in Diet and PA Interventions—Using items we developed specifically for this study, survivors rated their interest in learning more about weight control, eating better to stay healthy, or getting in shape. The items were rated on a 5-point Likert scale from 1 (extremely) to 5 (not at all) interested. Respondents were also asked to rate their interest in different modes of intervention delivery (i.e., clinic-, camp-, telephone-, mail-, or computer-based) on a similar 5-point Likert scale.

Statistical Analysis

Descriptive statistics were computed for each of the major study variables, and the percentages of survivors meeting national guidelines for diet and PA were calculated. One-sample t-tests compared the percentages of study participants meeting national guidelines with available population norms. Chi-square tests were used to assess group differences in the percentage of survivors meeting national guidelines. Pearson correlations were conducted to examine associations between lifestyle behaviors and HRQOL. Univariate analyses of variance and t-tests were conducted to examine mean differences in HRQOL, weight status, and lifestyle behaviors based on demographic and medical variables. T-tests were also conducted to determine mean differences in HRQOL between survivors who met national guidelines for diet and PA, and those who did not. P values ≤ 0.05 were considered statistically significant.

RESULTS

Sample Characteristics

Of the 282 survey packets delivered, 170 were completed and returned, resulting in an overall response rate of 60%. No significant differences were observed between respondents and non-respondents on the basis of race, cancer type, and age at the time of the study. However, respondents were more often female, of younger age at diagnosis, and also more proximal to the time of diagnosis ($p = 0.05$ for each comparison), relative to non-respondents.

Respondents were relatively evenly divided between males (52%) and females (48%); most were non-Hispanic White (69%; Table 1). Eighteen percent of respondents were AYAs. The average length of time since diagnosis was 8.6 years ($SD=4.0$). Two thirds of the sample comprised survivors of CNS tumors or leukemia, with the remainder relatively evenly divided between survivors of lymphoma and sarcoma (Table 1).

Thirty-nine survivors (23%) indicated that they received assistance in completing all or part of the survey. T-tests were conducted to determine whether there were differences on the major study variables for those who completed their own surveys and those who received parental assistance. Compared with those who received assistance, respondents who completed their own surveys were older and more likely to have been diagnosed at a later age ($M=10.2$ years, $SD=5.5$ versus $M=5.3$ years, $SD=3.2$; $t(165)=-5.17$; $p=.001$). No other significant differences were found.

Weight Status and Lifestyle Behaviors

Descriptive statistics for self-reported weight status, food intake, and PA for which continuous scale scores could be calculated are detailed in Table 2. Results showed that the majority of survivors failed to meet national recommendation for fiber intake, F&V consumption, and PA. Slightly over half of survivors (55.6%) had a normal BMI. The remaining survivors were underweight (11.7%), overweight (19.1%), or obese (13.6%).

Chi-square analysis revealed significant differences in the percentage of survivors meeting national guidelines for BMI based on cancer type ($\chi^2=18.96$, $p<.05$). Specifically, the proportion of lymphoma survivors who were overweight or obese (43%) was greater than that in the other three groups. No significant differences in PA or dietary intakes were found based on cancer type. However, the proportion of male survivors who met the guidelines for fiber intake ($\chi^2=13.01$, $p<.0001$) and F&V consumption ($\chi^2=6.54$, $p=.01$) was greater than the proportion of female survivors. A non-significant trend ($p=.06$) also suggested that the proportion of child survivors who consumed lower fat diets was greater than the proportion of AYA survivors ($\chi^2=3.69$).

F&V consumption was significantly and positively associated with fiber intake ($r=.80$, $p=.001$), marginally positively associated with PA ($r=.16$, $p=.06$), and negatively associated with percent of energy from fat ($r=-.21$, $p=.03$). Fiber intake was significantly positively associated with PA ($r=.20$, $p=.04$), negatively associated with percent energy from fat ($r=-.26$, $p=.01$), and marginally negatively associated with BMI ($r=-.15$, $p=.10$). No other significant correlations were observed.

HRQOL, Weight Status, and Lifestyle Behaviors

Few significant associations were observed between HRQOL and weight status, diet, and PA. Modest but significant inverse correlations were observed between physical function and percent of energy from fat ($r=-.19$, $p=.05$) and between level of cancer worry and BMI

($r=-.17$, $p=.04$). In addition, individuals who had better physical function scores exercised more often ($r=.22$, $p=.01$), and those who reported more general fatigue ($r=.18$, $p=.04$) and cognitive fatigue ($r=.23$, $p=.01$) exercised less often. (Note: higher fatigue scores indicate less fatigue [or better functioning]).

To determine whether there were specific at-risk subgroups within our sample, we compared mean HRQOL values based on available survey data for developmental stage at time of cancer diagnosis (i.e., child or AYA survivor)², length of time since diagnosis, race, gender, and cancer diagnosis (i.e., CNS, lymphoma, leukemia, sarcoma). No significant differences were found for race and time since diagnosis, so these variables were dropped from further analysis.

Results of one-sample t-tests showed that CCSs had lower PedsQL summary scores and greater general and cognitive fatigue relative to healthy population norms regardless of developmental stage at time of diagnosis, gender, or cancer diagnosis (Table 3). Female and CNS tumor survivors had lower physical function scores than healthy population norms. AYA, female, and lymphoma survivors had more cancer worry concerns about physical appearance than healthy population norms. Lymphoma survivors also reported more pain than healthy population norms.

Univariate analyses of variance and t-tests were conducted to examine mean differences in HRQOL on the basis of sociodemographic and medical variables. No significant differences between child and AYA survivors were found. Post-hoc comparisons using Tukey's least significant difference test showed that female survivors reported significantly poorer physical functioning than did male survivors. (Table 3) In addition, two key differences emerged between diagnosis groups. First, survivors of CNS tumors and lymphoma reported significantly greater general fatigue and cancer worry relative to survivors of leukemia and sarcoma. Second, survivors of CNS tumors reported significantly greater cognitive fatigue and poorer physical function than the other three cancer diagnosis groups (Table 2).

Univariate analyses of variance and t-tests were conducted to examine mean differences in HRQOL, based on BMI and whether or not survivors met national guidelines for PA, F&V consumption, percent of energy from fat, and fiber intake. Significant differences were found for percent energy from fat and PA. Specifically, survivors who did not meet current recommendations for fat intake (i.e., >35% of their energy came from fat), experienced significantly ($t=-2.12$, $p=.04$) more general fatigue ($M=67.23$, $SD=25.98$) than those who did meet recommendations ($M=76.90$, $SD=22.24$); they also experienced significantly ($t=-2.10$, $p=.04$) more cognitive fatigue ($M=63.75$, $SD=25.11$) than those who did meet recommendations ($M=73.77$, $SD=23.19$). Note: lower scores indicate greater fatigue. There was also a trend ($p=.10$) for CCSs who did not meet national recommendations for fat intake to have poorer physical HRQOL ($t=-1.65$). In terms of PA, individuals who had greater cancer worry ($M=61.37$, $p=.25.51$) were significantly more likely to be meeting guidelines for PA ($t=2.29$, $p=.02$) than those who had less cancer worry ($M=71.42$, $SD=25.13$). There were also trends ($p=.10$) for those who were not meeting PA guidelines to report higher levels of general fatigue ($t=-1.62$) and poorer physical HRQOL ($t=-1.65$).

²Given the wide range in attained developmental age in our sample, we also examined differences in HRQOL and intervention preferences based on whether an individual was 14 years old at time of survey completion or 15–29 years old at time of survey completion. The results for these analyses did not significantly differ from the results for the analyses conducted based on developmental stage at time of diagnosis (child or AYA) with the exception that survivors who were age 15–29 at time of survey completion were significantly ($t=2.41$, $p<.05$) more likely to prefer mail based interventions ($M=1.84$, $SD=.78$) than those who were age 14 or less at time of survey completion ($M=2.15$, $SD=.76$).

Intervention Preferences

As Table 4 shows, 75% of survivors were “very” or “extremely” interested in participating in weight control programs, 84% in learning to eat more nutritiously, and 87% in getting in shape. T-tests were conducted to examine mean differences in preferences for intervention topics and mode of delivery based on age group, gender, cancer diagnosis, and whether or not survivors scored above or below national norms for general or cognitive fatigue. These two specific aspects of HRQOL were chosen for comparison because CCSs in the current study reported significantly higher levels of both general and cognitive fatigue relative to age-matched healthy population norms regardless of age group, gender, or cancer diagnosis, and because fatigue is often a key outcome of lifestyle interventions that target HRQOL [60; 61]. Findings for general and cognitive fatigue were similar, so only the results for general fatigue are shown. In addition, no significant mean differences in intervention preferences were found for cancer diagnosis, so these results were also not shown.

In terms of preferences for intervention topic, significant differences were noted for gender. Specifically, female survivors were significantly more likely to endorse diet or weight control interventions than male survivors. In terms of preferences for mode of intervention delivery, most survivors preferred mail- or computer-based programs (Table 4). However, when preferences were examined by sub-groups, child survivors were more likely to favor camp-based programs and female survivors were significantly more likely to favor mail- and computer-based programs ($p = .05$). Survivors who scored below the national norms for general and cognitive fatigue were more likely to prefer clinic-, telephone, and mail-based programs than survivors who had better than average HRQOL.

DISCUSSION

This is one of very few studies to document the diet and exercise behaviors of survivors of childhood cancer and associate these behaviors with specific HRQOL domains. It is also one of the first studies to examine whether HRQOL, lifestyle behaviors, and intervention preferences differ among CCSs on the basis of group-level characteristics (e.g., developmental stage at time of diagnosis, gender, cancer diagnosis). Overall, our findings suggest that females, AYAs and CNS and lymphoma survivors are CCS population subgroups that are potentially “at risk” for poor dietary practices, sedentary behaviors, obesity, and poor HRQOL. Moreover, survivors in these three subgroups were generally more interested in participating in diet and PA interventions than were survivors in the other subgroups (i.e., males, child survivors, and leukemia and sarcoma survivors). Given this increased need and interest, our findings suggest that future research should focus on developing diet and PA interventions to improve HRQOL that target these groups.

Sixty one percent of the survivors in this sample consumed lower fat diets. The reported rates of overweight or obesity (cumulatively 45%) are concerning because they far exceed the healthy population norm of 17% for children and adolescents in the U.S. [62]. Lack of PA and the proportion of time spent engaging in sedentary behaviors (e.g., television watching) are possible contributing factors. Indeed, the amount of time survivors actually spent engaging in PA could have been inflated due to self-report and social desirability bias. More studies are needed that record actual PA, such as with the use of accelerometers or other devices.

PA and diet often go hand-in-hand, so the amount of PA in which survivors engaged may not have been sufficient to offset a poor diet. Because the amount of time devoted to sedentary behaviors was not assessed, quantifying time spent engaged in PA may not by itself provide an accurate portrait of this population. Moreover, the low adherence to national recommendations for PA may have been due to a number of personal barriers

unique to CCSs. For example, our findings for HRQOL suggest that fatigue may be a distinguishing feature in this population. Thus, studies designed to increase PA in this population should consider advocating PA early in the day, before fatigue sets in. Programs that encourage working through fatigue will also likely be necessary.

Lymphoma survivors were significantly more likely to be overweight or obese than survivors of other cancers. Existing large-scale published studies have shown that high BMI is prevalent among survivors of acute lymphoblastic leukemia; however, those studies compared survivors to published norms for healthy individuals or to siblings [63–65] and not to survivors of other childhood cancers, as we have. Although causality cannot be determined due to the cross-sectional nature of the data, high BMI may be at least partially attributable to the fact that the lymphoma survivors reported poorer physical functioning and greater fatigue than did other cancer survivors. Radiation treatment may be another contributing factor [64].

Whereas the proportion of survivors who did not meet recommendations for F&V consumption (76%) was only slightly higher than national averages (65–73%) [66], fiber intake was far below national guidelines. Thus, in some respects, study participants had a more problematic risk profile than did their age-matched peers nationally. This pattern is similar to other published studies of health behaviors among CCSs [67] and is troubling because of the increased vulnerability of this group to illnesses [64; 68] such as cardiovascular disease and diabetes, in which both low dietary fiber [69; 70] and obesity [71; 72] are thought to play important roles. Because ours is one of the first studies to report on the dietary habits of CCSs, more research is needed to adequately quantify dietary intake. Prospective studies that use full-scale instruments and risk-based guidelines would be particularly desirable [11].

Our findings for HRQOL and its relation to lifestyle behaviors and group-level characteristics such as gender, cancer diagnosis, and developmental stage at time of cancer diagnosis is an important contribution to knowledge of CCSs and suggests several important avenues for future research. First, the cancer survivors in the current study reported significantly higher levels of both general and cognitive fatigue relative to healthy population norms regardless of these group-level characteristics. However, when other aspects of HRQOL such as physical function, cancer worry, bodily pain, and physical appearance were examined, significant differences emerged. For example, female survivors had poorer physical functioning than male survivors, and they had more cancer worry and physical appearance concerns than healthy population norms, suggesting that poorer HRQOL may motivate interest in lifestyle interventions for this group. Supporting this idea, we also found that female survivors expressed greater interest in participating in interventions that focus on eating better to stay healthy than did male survivors. Taken together, our findings suggest that it is critical to consider group-level characteristics when developing targeted interventions to improve aspects of HRQOL.

Another important finding that emerged was that survivors of CNS tumors and lymphoma reported poorer physical functioning than did survivors of leukemia and sarcomas. Although the type of cancer treatment was not assessed in this study, the fact that patients with CNS tumors and lymphoma often undergo cranial radiation may account for their poorer relative HRQOL [64]. Moreover, although the fact that we did not assess treatment type limited the study, focusing on a single cancer diagnosis, as the vast majority of studies of CCSs have done may not have revealed that CNS and lymphoma survivors have poorer HRQOL than other survivors. While future studies may benefit from larger, more diverse samples, and greater attention to treatment type, this study represents an important first step in understanding the differential impact of cancer diagnoses on various aspects of HRQOL.

Few significant associations between HRQOL and lifestyle behaviors were found. However, as might be expected, the amount of energy that survivors obtained from fat was inversely related to their physical functioning. An unexpected observation was that survivors who worried more about cancer had higher BMI. It may be useful for future diet and exercise interventions targeting this population to include components that address survivors' worry about cancer, their concerns about physical exertion, and stress/emotional eating.

Finally, our HRQOL findings underscore the idea that significant differences in HRQOL exist among CCSs depending on adherence to national dietary guidelines. Moreover, HRQOL may drive not only interest in and receptivity to lifestyle interventions, but also preferences for mode of intervention delivery. Indeed, overall interest in diet and PA interventions was high across CCSs and those who reported higher than average levels of fatigue (relative to other study participants) were more interested in participating in such interventions than those with better than average (lower) levels of fatigue. Those with higher than average fatigue were also the most interested in participating in clinic-, mail-, or telephone-based interventions. Given the study respondents' need for and receptivity to intervention, more research is warranted to identify and overcome the possible challenges of implementing lifestyle interventions in these health-compromised populations. Attention should also be devoted to defining metrics for improvement, and retaining these individuals in lifestyle programs.

This study's strengths include the use of valid and reliable measures of HRQOL, PA, and dietary intake, and its examination of a potential relationship between group-level variables and HRQOL, weight status, and lifestyle behaviors. This study's limitations include the fact that information about socioeconomic status was not collected. In addition, the sample was predominantly non-Hispanic White (69%) and there was insufficient variability to explore differences based on race and ethnicity. Nevertheless, the sample was more diverse than that of other published studies of CCSs [10; 67]. An additional limitation is that developmental changes over time were not assessed and thus causality could not be inferred. Data on social desirability bias were not collected so it was impossible to know whether some individuals were more likely than others to report better adherence to guidelines. Finally, more precise measures of weight status and diet as well as measures capturing perceived barriers to engaging in healthy lifestyle behaviors and quantifying the amount of time spent engaging in sedentary activities (e.g., playing video games, using the internet, and watching television) might have yielded stronger results.

Conclusion

Our findings underscore the need to address modifiable risk factors such as diet and PA and highlight the idea that the effort to reduce the prevalence of obesity among CCSs should focus on increasing energy expenditure (PA) as well as reducing energy intake (dietary fat). More research is needed to identify barriers to a healthy lifestyle in this population and to determine whether interventions that simultaneously address diet and PA have a greater likelihood for reducing risk and improving survivors' quality of life than interventions that only address a single behavior [67].

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Table 1

Demographic and disease characteristics of the study sample (N = 170)

	N (%)	M (SD)	Range
Sex			
Male	88 (52)		
Female	82 (48)		
Race			
Non-Hispanic white	118 (69)		
Non-white	52 (31)		
Age at Survey *		17.7 (5.6)	3.3 – 28.9
Developmental stage at time of diagnosis *		9.1 (5.5)	.27 – 20.1
Child (0 to 14 years)	137 (81)		
AYA (15 to 29 years)	30 (18)		
Length of time since diagnosis (years)		8.6 (4.0)	1.4 – 16.7
Education ^a			
At least some college	59 (73)		
Employed ^a			
Yes	42 (52)		
Cancer Type			
CNS	55 (32)		
Leukemia	55 (32)		
Lymphoma	28 (17)		
Sarcoma	32 (19)		

Note: N= Sample size; M= mean; SD= standard deviation; CNS=central nervous system tumors; AYA = adolescent and young adult;

* 3 survivors did not provide their date of birth on the questionnaire, so age could not be calculated;

^a Analysis based only on participants 18 years and older

Table 2

Weight status and lifestyle behaviors of the study sample (N=170)

	Mean (SD)	Range	Percentage meeting guidelines^a
BMI (kg/m ²)	22.2 (5.2)	13.5 – 50.6	56%
Fruit and vegetable intake (servings/day)	4.1 (1.7)	1.1 – 9.2	24%
Fiber intake (g/day)	16.7 (5.9)	7.5 – 34.5	4%
Energy from fat (%)	33.0 (6.2)	15.4 – 60.00	61%
Physical activity (minutes/week) ^{b,c}	164.4 (125.8)	0 – 564.00	35%

Note:

^aFor fruit and vegetable intake, percentages refer to those consuming five or more fruit and vegetable servings per day. Percentages of those meeting guidelines for fiber intake are based on grams consumed as a function of assumed age-appropriate energy intakes and used cut points recommended by the Food and Nutrition Board of the Institute of Medicine. For dietary fat intake, those meeting national guidelines consumed 20–35% of their energy from fat; for physical activity, those meeting national guidelines are based on a single item from Youth Risk Behavior Survey.

^bMeans and standard deviations are for Godin minutes of moderate and vigorous physical activity per week.

^cFive cases were removed from the calculation for physical activity because they were outliers (>2SD over the mean).

Descriptive results for PedsQL Subscales

Table 3

	Healthy population norms		Developmental stage at cancer diagnosis (n=167) [^]			Sex (n=170)			Cancer diagnosis (n=170)				
			Child survivor Mean (SD)	AYA survivor Mean (SD)	t	Female Mean (SD)	Male Mean (SD)	t	CNS Tumors Mean (SD)	Leukemia Mean (SD)	Lymphoma Mean (SD)	Sarcoma Mean (SD)	F
Physical function	83.41 (17.26)	79.53 (20.88)	77.20 [#] (22.36)	77.20 [#] (22.36)	1.38	75.75 [#] (21.14)	82.89 (20.56)	-2.15[*]	72.26 ^{a#} (26.19)	82.37 ^b (17.37)	79.57 (18.69)	85.82 ^b (16.73)	3.26[*]
General fatigue	85.34 (14.95)	73.38 [#] (24.35)	65.77 [#] (26.99)	65.77 [#] (26.99)	.07	68.93 [#] (24.18)	75.10 [#] (25.39)	-1.58	67.47 ^{a#} (26.69)	75.88 ^{b#} (21.07)	65.74 ^{a#} (25.04)	79.17 ^{b#} (26.03)	2.45[*]
Cognitive fatigue	81.14 (17.43)	66.60 [#] (25.26)	66.96 [#] (26.35)	66.96 [#] (26.35)	1.56	65.15 [#] (25.02)	68.45 [#] (26.30)	-.79	58.25 ^{a#} (26.92)	73.23 ^{b#} (23.16)	68.27 ^{b#} (22.36)	69.97 ^{b#} (25.84)	3.18[*]
Cancer worry	75.92 (28.35)	69.65 (25.72)	61.61 [#] (24.36)	61.61 [#] (24.36)	.69	65.13 [#] (25.23)	71.40 (25.55)	-1.51	65.99 ^{a#} (25.11)	71.20 ^b (27.93)	58.65 ^{a#} (26.19)	75.86 ^b (18.55)	2.50[*]
Physical appearance	76.21 (25.00)	70.76 [#] (26.69)	66.67 [#] (28.60)	66.67 [#] (28.60)	1.42	66.89 [#] (25.77)	73.42 (27.92)	-1.49	72.50 (26.69)	72.41 [#] (26.44)	67.31 [#] (27.98)	64.94 [#] (27.76)	.68
Bodily pain	74.74 (25.77)	72.08 (25.76)	64.29 [#] (26.29)	64.29 [#] (26.29)	1.05	68.91 (25.21)	72.80 (26.61)	-.92	70.00 (25.63)	72.22 ^a (27.16)	61.06 ^{b#} (27.23)	78.87 ^a (20.89)	2.29[*]

Note:

[^] Three survivors did not provide their date of birth on the questionnaire, so age could not be calculated. Higher scores indicate better QOL (fewer problems). SD=standard deviation; F = F-tests for analyses of variance testing between group mean differences; t = t-tests testing between group mean differences. Means with different letter superscripts (a, b) are significantly different based on post-hoc comparisons using Tukey’s LSD.

[#]PedsQL subscale scores were significantly different population norms reported by Varni et al., 2002;

^{*} p < .05;

^{**} p < .01

Table 4
Survivor interest in various intervention topics and modes of delivery and differences in intervention preferences based on sociodemographic factors and survivor HRQOL

Intervention topic	Survivors who were interested	Developmental stage at time of diagnosis ^a			Gender ^d		General fatigue ^d			
		%	Child survivors Mean (SD)	AYA survivors Mean (SD)	t	Female Mean (SD)	Male Mean (SD)	t	Below National Norm ^b Mean (SD)	Above National Norm ^b Mean (SD)
Weight control	75	1.73(.86)	1.93(.83)	--		1.68(.77)	1.86(.92)	--	1.81(.81)	1.84(.87)
	84	1.62(.76)	1.53(.73)	--		1.48(.67)	1.73(.81)	2.08[*]	1.53(.72)	1.74(.76)
	87	1.51(.71)	1.63(.76)	--		1.50(.67)	1.60(.77)	--	1.50(.70)	1.62(.75)
Mode of intervention delivery										
Clinic based	62	2.10(.77)	2.30(.84)	--		2.04(.77)	2.24(.79)	--	2.02(.77)	2.36(.76)
	57	2.07(.84)	2.47(.73)	2.43[*]		2.02(.83)	2.26(.82)	1.87[^]	2.17(.82)	2.08(.86)
	46	2.45(.68)	2.17(.83)	1.96[*]		2.34(.71)	2.47(.72)	--	2.35(.75)	2.55(.63)
Mail based	72	1.99(.76)	1.73(.83)	1.61[^]		1.78(.77)	2.10(.76)	2.74[*]	1.85(.78)	2.14(.74)
	74	1.84(.81)	1.73(.87)	--		1.70(.78)	1.95(.86)	1.96[*]	1.77(.79)	1.97(.86)

Note: Percentages are based on the number of survivors who indicated they were either extremely or very interested in a particular topic of intervention or mode of intervention delivery; M = Mean, SD = Standard deviation.

^a Scores ranged from 0 (extremely interested) to 5 (not at all interested).

^b The national norm for the PedsQL general fatigue score is based on Vami et al (2002) and is M=85.34, SD=14.95. Differences in intervention preferences were examined for those scoring above versus those scoring below this national norm;

* p < .05,

** p < .001,

[^] p < .10.