Published in final edited form as:

J Cancer Surviv. 2013 March ; 7(1): 1–19. doi:10.1007/s11764-012-0249-3.

Development of a Comprehensive Health-related Needs Assessment for Adult Survivors of Childhood Cancer

Cheryl L. Cox, PhD^a, Deborah A. Sherrill-Mittleman, PhD^a, Barth B. Riley, PhD^b, Melissa M. Hudson, MD^c, Lauren J. Williams, BA, CRA^a, Wendy M. Leisenring, ScD^d, Margie G. Zacher, CRA, CCRP^a, and Les L. Robison, PhD^a

Cheryl L. Cox: cheryl.cox@stjude.org; Deborah A. Sherrill-Mittleman: deborah.mittleman@stjude.org; Barth B. Riley: barthr@uic.edu; Melissa M. Hudson: melissa.hudson@stjude.org; Lauren J. Williams: lauren.williams@stjude.org; Wendy M. Leisenring: wleisenr@fhcrc.org; Margie G. Zacher: margie.zacher@stjude.org; Les L. Robison: les.robison@stjude.org

^aDepartment of Epidemiology and Cancer Control, 262 Danny Thomas Place, St. Jude Children's Research Hospital, Memphis, TN 38105-3678

^bDepartment of Health Systems Sciences, University of Illinois-Chicago, 845 S. Damen Avenue, Chicago, IL 60612

^cDepartment of Oncology, 262 Danny Thomas Place, St. Jude Children's Research Hospital, Memphis, TN 38105-3678

^dDepartment of Clinical Statistics and Biostatistics Fred Hutchison Cancer Research Center, 1100 Fairview Ave. N. P.O. Box #19024, Seattle, WA 98109-1024

Abstract

Purpose—Examine the construct validity, stability, internal consistency, and item-response performance of a self-report health needs assessment for adult survivors of childhood cancer.

Methods—A 190-item mailed survey was completed by 1,178 randomly-selected (stratified on age, diagnosis, time since diagnosis) Childhood Cancer Survivor Study participants (mean age: 39.66 [SD: 7.71] years; time since diagnosis: 31.60 [SD: 4.71] years). Minorities and rural residents were oversampled at a 2:1 ratio.

Results—The final instrument included 135 items comprising 9 unidimensional subscales (*Psycho-Emotional, Health System Concerns, Cancer-related Health Information, General Health, Survivor Care and Support, Surveillance, Coping, Fiscal Concerns, and Relationships*).

Confirmatory factor analysis ($n=1,178$; RMSEA = 0.020; 90% CI = 0.019–0.020; CFI = 0.956; TLI = 0.955) and person-item fit variable maps established construct validity. Across subscales, Cronbach's alpha was 0.94–0.97 and the 4-week test-retest correlations were 0.52–0.91. In a Rasch analysis, item reliability was 0.97–0.99, person reliability was 0.80–0.90, and separation index scores were 2.00–3.01. Significant subscale covariates of higher need levels included demographics, diagnosis, and treatment exposures.

Conclusions—The Childhood Cancer Survivor Study Needs Assessment Questionnaire (CCSS-NAQ) is reliable and construct-valid, has strong item-response properties, and discriminates need levels.

Implications for Cancer Survivors—The CCSS-NAQ potentially can be used to: 1) directly assess adult childhood cancer survivors' self-reported health-related needs, 2) identify individuals

Corresponding Author: Cheryl L. Cox, PhD (cheryl.cox@stjude.org) Department of Epidemiology & Cancer Control, St. Jude Children's Research Hospital, 262 Danny Thomas Place, Memphis, TN 38105-2794, (901) 595-4789; FAX: (901) 595-2866.

CONFLICT OF INTEREST:

The authors declare that they have no conflicts of interest.

or subgroups with higher-level needs, 3) inform prevention and direct intervention strategies, and 4) facilitate prioritization of health-care resource allocation.

Keywords

survivors; pediatric cancer; health-related needs; psychometrics; Rasch model

Introduction

Nearly one in 640 young adults 20 to 39 years of age [1] is a childhood cancer survivor [2]. Forty-four percent of the >10,000 active participants in the Childhood Cancer Survivor Study (CCSS), North America's largest cohort of pediatric cancer survivors, are now 41 or more years of age, and 7.3% are 52 years of age or older. The number of older childhood cancer survivors will grow at an even greater rate in the future, putting increasing demands on the health care system. Great progress has been made in beginning to document the late morbidity, mortality and treatment effects of childhood cancer in this population [3, 4]; however, we know very little about survivors' health-related needs and how these needs affect their adult lives. Pediatric cancer therapies can affect all aspects of a survivor's life: physical, psychological, social, economic, and existential; the impact of therapy will precipitate different survivor needs as the survivor ages owing to the heterogeneity of cancer, treatment exposures, survivor behavior, and access to informed health care [5].

Providers recently have been challenged to address the broad spectrum of health-related needs of survivors [6]. While evidence suggests that patients want providers to ask about their health-related needs, assessment is often unsystematic and providers frequently only focus on specific presenting problems [7]. Lack of satisfaction with care [7, 8], professionals' varying ability to elicit relevant information, and patients' inability or reluctance to volunteer their concerns and anxieties all contribute to poor documentation of needs. To better inform flexible models of care to accommodate survivors who may have differing needs and circumstances, we must first document survivors' perceptions of the needs that they confront [9]. Longitudinal studies that rely on broad-based needs assessment measures will avoid fragmented data collection and investigator bias in the need domains studied. To meet the need for the development of a comprehensive health-related needs assessment for adult survivors of pediatric malignancies, we introduce the Childhood Cancer Survivor Study (CCSS) Needs Assessment Questionnaire (CCSS-NAQ) and apply classical test theory and Rasch modeling to assess its psychometric and item-response properties. Our primary purpose was to create a multidimensional instrument with stand-alone latent constructs (subscales).

Background

Needs assessment in survivors of childhood cancer

Very few studies have examined childhood cancer survivors' perceived health-related needs. More than 60% of 879 young adults with a variety of pediatric malignancies (age 18–39 years) expressed a need for age-appropriate cancer-related information about exercise, nutrition, complementary and alternative health services, and infertility [10]. Parents and families of children with different pediatric cancer diagnoses, reported a need for information about follow-up recommendations, diagnostic findings, the role of health care providers in long-term management, lifestyle, family stress, school issues [10], and late-effects risks [10, 11]. Using phenomenological analysis [9], three themes were identified among 26 survivors (13–25 years) and their parents – strategies to achieve a normal life, expectations about follow-up, and preferences for different models of care. Subjective and objective health care needs related to utilization of health care services were assessed in 335

survivors 18 years; the majority had no regular follow-up visits and 42% of this group reported that they missed not having one. More than one-third of the total group surveyed was dissatisfied with their follow-up programs because they did not meet their needs [12]. More recently, 526 adult survivors of childhood central nervous system (CNS) tumors [13] identified psychosocial services (40%), education about their illness (35%), care coordination (22%), and medical care (15%) as their most pressing needs.

These studies were based on limited need domains, limited psychometric assessment of the measures used, and relied on convenience samples that did not adequately represent minority and rural populations. None of the studies reported the needs of childhood cancer survivors older than 40 years - the population most likely to experience multiple health-related needs as a result of their escalating chronic illnesses and complications of late effects [14].

Methods

Instrument development

We reviewed 57 studies that quantified unmet needs in survivors of adult cancer across 14 cancer diagnoses; the majority of these studies focused on breast, prostate, or colorectal cancers. From this literature, we identified 9 instruments [15, 16, 17–27] specific to survivor-perceived health-related needs that demonstrated: 1) subscale Cronbach's alphas between 0.70 and 0.90 [28]; 2) evidence of face, content, and construct validity[29]; 3) acceptable completion times (30 minutes or less); 4) reading levels between grades 4 and 8 [30], and 5) use with multiple samples. Each instrument was initially informed through focus groups of adult cancer survivors. The number of items per instrument ranged from 9 to 144 and the number of domains assessed per instrument ranged from 1 to 8.

Collectively, these 9 measures contained 17 need domains, identified by their developers, which our study team (physicians, advanced practice nurses, survivor clinic nurses, and senior childhood cancer survivor investigators) endorsed unanimously as being important content to include in a comprehensive needs assessment of childhood cancer survivors. These domains included: psychological, emotional, health system information, cancer-related health information, physical and daily living, patient care and support, surveillance, sexuality/reproductive, coping, social/economic, relationships, expectations, life perspective, transportation, employment, insurance, and spiritual. Many of the domains overlapped across instruments; again, consensus was reached among the expert panel as to which set of items would best represent that domain. This strategy offered the distinct advantage of utilizing previously defined domains and tested items that had demonstrated reliability and validity.

Items that were geared to survivors who continue to receive therapy, who are at the end of life, or who are regularly re-admitted to inpatient care were eliminated from consideration. Items that focused on the interpretation of laboratory or pathology reports during the course of active treatment or items specific to a single diagnosis were also not considered, as these issues are largely irrelevant to the experience of the childhood cancer survivor. Absent from these instruments were surveillance items that addressed needs related to long-term management/follow-up and screening for treatment-related late effects. Items representing this content were taken from the CCSS questionnaires [31] and added to the surveillance domain. The final instrument contained 190 items and the 17 previously identified domains were hypothesized as 17 discrete subscales.

The instrument was tested for feasibility in a pilot study of 51 childhood cancer survivors (21 males; 30 females) 25 years of age or older who were followed in the St. Jude

Children's Research Hospital (St. Jude) survivor clinics. The CRA approached potential participants, ascertained that they were at least 25 years of age, willing and able to respond to the questionnaire, and solicited their participation as they awaited their follow-up appointments. The data were collected anonymously and gender was the only identifying survivor characteristic. In addition to responding to the 190 items, the survivors provided the following input: 1) *How well do you think the items in the survey covered the needs of childhood cancer survivors* ("Very well" n=45; "Somewhat" n=6); no survivor endorsed the "neutral" "fair", or "not at all" options. 2) *How comfortable were you in answering items about your personal needs* ("very comfortable" n=47; "somewhat comfortable" n=4); 3) *What health-related needs have you experienced that are not addressed here*; no one provided a response to this question. Time to complete the questionnaire ranged from 20–30 minutes.

Additionally, a small focus group (6 participants) led by the project RA, addressed the extent to which the instrument covered need domains important to childhood cancer survivors and the item/response readability/comprehension. The group felt that the needs of childhood cancer survivors were "very well addressed" and that the instructions and response items, with few exceptions, were clear. Selected items were eliminated and new items were written based on the survivors' input. The new items were then reviewed and endorsed by the expert panel. The reading level (Flesch-Kincaid formulae) of the instrument was 4th–5th grade.

Data and sample source

The CCSS is a 27-institution cohort study that currently follows more than 10,000 geographically and socio-economically diverse long-term survivors (i.e., those who completed therapy for pediatric malignancy at least five years previously) [32, 33]. The IRB-approved (at each participating institution) retrospective study was initiated in 1994 to examine late effects in survivors of pediatric cancers diagnosed and treated between 1970 and 1986. Survivors completed a baseline questionnaire at study entry and respond to follow-up questionnaires at regular intervals. All but 10% of the cohort consented to release their medical records. Questionnaires and sampling methods have been detailed by Robison et al. [32, 33] and are available at <http://ccss.stjude.org>.

Sample

CCSS participants who were treated at St. Jude were not eligible for the study, as financial and continuing care options at St. Jude differ from those at the 26 other participating CCSS institutions. Exclusion of these survivors assured a more homogeneous sample in terms of the cancer treatment experience and survivors' need perceptions. CCSS participants reflect the prevailing pediatric cancer diagnoses; leukemia, tumors of the central nervous system, neuroblastoma, non-Hodgkin lymphoma, Wilms tumor, Hodgkin disease, and solid tumors (rhabdomyosarcoma, osteosarcoma, and Ewing sarcoma) [34]. An exception is the diagnosis of retinoblastoma. The National Cancer Institute has a separate follow-up study [35] for children with this diagnosis and consequently these survivors are not followed in the CCSS cohort study. We limited the sample to survivors 25 years of age as of December 31, 2009 to focus on a group unlikely to be covered by parental health insurance or by federal/state insurance for children and adolescents. Adults with severe cognitive impairment who rely on parents/spouse to complete their CCSS follow-up questionnaires were excluded from the sample. An initial sample of 4,454 CCSS participants met the study's eligibility requirements.

We sought a final sample of 1,000 useable questionnaires. Sample size was based on our proposed analyses: 1) factor analysis requires a 1:5 item-respondent ratio [36]; 2) the longest

subscale contained 28 items; a sample size of 500 subjects is adequate to recover item characteristic curves for scale lengths as short as 30 items for the two-parameter Rasch model and 1000 subjects are adequate for a 3-parameter Rasch model [37]. Therefore, a sample size of 1,000 evaluable questionnaires would be more than sufficient for both our classical and item-response theory approaches [28]. A stratified (age, gender, diagnosis) random sample of 1,430 survivors (RANUNI, SAS) was initially drawn from the total eligible sample on the basis of previous CCSS cohort response rates. When survivors did not respond within four weeks, their names and contact information were given to our tracing and survey call center; once 10–13 calls were attempted at different times (including nights and weekends) without reaching the survivor and the survivor did not respond to a subsequent reminder mailing, that survivor was replaced with the next individual randomly assigned to the relevant stratum. African-American, Hispanic, and rural-residing (i.e., whose Rural Urban Commuting Area Code was tied strongly or weakly to a small town or who resided in isolated, smaller rural census tracts) survivors were over-sampled at a 2:1 ratio to maximize heterogeneity. A total of 3,090 survivors were sent a questionnaire; a highly mobile cohort, many of them could not be located through tracing procedures. For each 100 completed questionnaires returned, we mailed a second questionnaire to 10 of those individuals in order to assess the instrument's short-term stability. This strategy assured sampling the entire range of respondents and avoided biasing this analysis to early responders. The second questionnaire was mailed within two weeks of receipt of the first questionnaire, with a request to return it upon receipt. Figure 1 provides a detailed description of the final sample. All study participants were given their choice of a \$25 check or gift card for each questionnaire completed.

Data collection

The questionnaire booklets were mailed to participating survivors with a pre-addressed, pre-stamped return envelope and included needs assessment and demographic, socioeconomic, and health care access questions.

Study measures

One concern inherent to needs assessments [38] is that they document needs as opposed to existing problems. For example, survivors may have problems not viewed as needs because they are receiving sufficient help. We designed item-response options for the CCSS-NAQ that allowed respondents to indicate that there was no need, because either (1) no need existed or (2) the need was met, or that there was a low (3), moderate (4), or high (5) level of need. Additional questions followed the needs assessment: 1) *“How well do you think the items in the survey covered the needs of childhood cancer survivors”* (1= “Not at All”; 5= “Very Well”). 2) *“If you have experienced a need that was not listed in the questionnaire, please write it in the space below”*. 3) *“To what extent did you feel comfortable answering items about personal problems”* (1= “Very Uncomfortable”; 5= “Very Comfortable”); 4) *“Please list the five biggest needs you feel you have as a result of having had cancer”*.

Demographic and socioeconomic variables included: sex, race, marital status, two indicators of economic status (highest household education and household income), household membership (number of adults and children in the household and their relationship to the participant), number of ill children and adults requiring care, and the survivor's employment status. Insurance status, health care access, and regular source of primary care were assessed by using index items from the National Health Interview Survey [39] and the CCSS cohort survey [32, 33]. Data related to childhood cancer (date of diagnosis, interval since diagnosis) were obtained from the medical records of the CCSS database.

Analyses

Classical test theory (CTT) and item-response theory (IRT) were used to evaluate the CCSS-NAQ. Whereas in CTT raw scores from an instrument can be interpreted only in the context of the specific items and sample used to create them, the Rasch measurement model [40, 41] can produce measures that are independent of the specific items and sample. The Rasch model evaluates the probability that a certain response to a questionnaire item is a function of the person's ability on the underlying dimension being measured by the scale and the difficulty of the item [42, 43]. As an example, we would produce similar person-trait estimates if we used another set of items measuring the same construct, and we would obtain similar item calibrations if we used another sample of respondents. CTT assumes that measurement error is homogeneously distributed among individuals. In Rasch and other IRT models, however, measurement error is specific to the person's trait level (e.g., extent of health-related needs) [44]. Both approaches provide important information about the suitability of the items to represent the construct(s) of "health-related needs" in childhood cancer survivors; IRT additionally addresses the ability of the scale(s) to capture all levels of "health-related needs" with equal precision.

Results

Sample

Despite a low response rate (39%) (Fig. 1), the sampling strategy yielded 1,178 usable surveys, more than meeting the target of 1,000 evaluable questionnaires. The sample was predominantly female, non-Hispanic white, married, college educated, and employed full-time with a median annual income of \$60,000–\$80,000 (Table 1). Non-respondents were slightly more racially diverse but predominantly white (85%); 4.6% were African American and 7.6% were Hispanic ($X^2[3] = 14.12$; $P = 0.003$), and more than half were male (51.2%; $X^2[1] = 42.62$; $P < 0.001$). Although most responders and non-responders were urban dwellers, rural survivors were well-sampled (15.4% of responders and 10.5% of non-responders were rural residents ($X^2[1] = 15.64$; $P < 0.001$). Treatment exposures were unknown for 10.84% of non-responders in contrast to only 5.94% of responders ($X^2[5] = 26.98$; $P < 0.001$). Non-responders were not found to differ significantly from the study sample in age, age at diagnosis, type of diagnosis, treatment exposures, or years since diagnosis; this may be due in part to our stratified sampling scheme.

Construct validity

Confirmatory factor analysis (CFA) [Mplus Version 6.1; Muthén and Muthén, Los Angeles, CA] was used to determine whether the dimensional structure of the CCSS-NAQ conformed to the 17 hypothesized domains. CFA supported the originally hypothesized 17-factor model ($n=1178$; RMSEA = 0.020; 90% CI = 0.019–0.020; CFI = 0.956; TLI = 0.955, probability RMSEA $\leq 0.05 = 1.000$), exceeding the established criteria for model acceptability (RMSEA ≤ 0.05 , CFI and TLI ≥ 0.95) [45]. Items from the employment, transportation, insurance, and financial/economic dimensions formed a higher-order factor in subsequent analyses, which we labeled *Fiscal Concerns*. Items from the *Life Perspective* dimension fit well with the *Coping* dimension and were retained on that scale (Table 2). In subsequent Rasch analyses, the sexuality, nutrition, services, and spirituality subscales failed to meet acceptable fit criteria and were dropped from further analyses.

Rasch analysis (Winsteps Version 3.72.3 (Beaverton, OR) provides a person-variable map as an additional measure of construct validity [46]. Ideally, the items should form a "ladder" [47] with more commonly occurring needs at the bottom and less commonly occurring needs at the top. The logit scale combines person ability (i.e., level of need) and item difficulty. The mean item difficulty is defined as zero, with equal intervals represented

above and below the mean. For example, on the *Cancer-related Health Information* subscale, items INS41 (“need info about cancer recurrence”) and INS51 (“need info about how cancer affects life”) appear exactly at the mean difficulty estimate (zero). A person whose cancer-related information need level is estimated to be zero on this scale has a 50% probability of endorsing both of these items, a >50% probability of endorsing items below zero (e.g., INS44, “need info about late effects of therapy”; INS46, “need info about diseases resulting from cancer therapy”), and a <50% probability of endorsing items above zero (e.g., INS43, “need info about what causes cancer”; INS45, “need info about what symptoms to report”). The 9-logit spread of item endorsement and the reasonable distribution of low-need and high-need endorsements suggest that survivors’ need for cancer-related information is adequately represented in this subscale’s 11 items.

The item order hierarchy was substantively meaningful for each subscale. Table 3 presents all retained items for each of the subscales; they are ordered from the most commonly endorsed items to the least commonly endorsed items. For the *Psycho-Emotional* subscale, items about worry (e.g., INS7, “need help dealing with worry”; INS5, “need help dealing with uncertainty about the future”) were commonly endorsed, whereas items related to maintaining emotional control (e.g., INS24 “need help with loss of control over emotions”) or adjustment to bodily changes (e.g., INS16, “need help dealing with fears about physical disability or deterioration”) were less commonly endorsed. For *Health System Concerns*, common needs addressed after-cancer care (e.g., INS28, “need information about important aspects of my after-cancer care”); less common were needs related to care access (e.g., INS30, “need help finding access to professional counseling”). Survivors commonly endorsed symptoms (e.g., INS59, “help with feeling tired”) on the *General Health* subscale, while health limitations (e.g., INS65, “need help with preparing meals or doing light housework or yard work”) were uncommon. In *Survivor Care and Support*, survivors frequently endorsed items about obtaining professional help (e.g., INS82, “need help to be able to see the specialists I need/want to see”), while problems with provider interaction (e.g., INS91, “need my physicians to be more accepting of me”) were less commonly endorsed. For *Surveillance*, need for general information about screening tests (e.g., INS107, “need information about what screening tests I need based on my treatment history”) were commonly endorsed, whereas need for screening test details (e.g., INS115, “need realistic information about how much time screening tests will take”) were less common. Commonly endorsed *Coping* items addressed dealing with having empathic support (e.g., INS119, “need opportunity to talk with someone who understands/been through similar experience”); less common needs dealt with life perspective (e.g., INS152, “need help trying to make my life count”). Insurance costs (e.g., INS185, “need help with insurance coverage for my other medical expenses”) were commonly endorsed in *Fiscal Concerns*; less common were transportation (e.g., INS164, “need help with transportation for work or household activities”) and job-related needs (e.g., INS171, “help with at-work concerns”). Items related to talking about cancer (e.g., INS146, “help having others acknowledge the impact of cancer on my life”) were commonly endorsed in *Relationships*, whereas items addressing interactions with children, spouse, or community (e.g., INS149, “help talking about my health with my family and friends”) were less common.

Rating scale analysis

Each of the subscales underwent rating scale analysis to examine the ordering of the scale points and determine whether each point was scored as predicted (i.e., a response of “3” has a higher threshold and average difficulty than a rating of “2”). There were underutilized rating scale categories in all subscales; we therefore restructured the rating scale by collapsing adjacent categories: “No need exists” = 1; “Need is satisfied” and “Low need” = 2; and “Moderate need” and “High need” = 3.

Unidimensionality

A principal components analysis of the standardized Rasch residuals was performed to assess the unidimensionality of each subscale. If the instrument measures a unidimensional construct, we would expect the remaining residual variance (i.e., after the Rasch factor has been extracted) to represent random stochastic variation (i.e., no remaining secondary structures [factors] in the data). The following criteria were used to confirm unidimensionality: >40% of the variance explained by the Rasch factor, an eigenvalue ratio of the Rasch measure to the first principal component ≥ 3 , and <15% of the residual variance explained by the first principal component [48, 49]. The total variance explained by the Rasch factors across the remaining 9 subscales was 45.2% (*Coping*) to 51.3% (*Psycho-Emotional*). The Rasch factor to first principal component ratio ranged from 3.13 (*Coping*) to 7.12 (*Psycho-Emotional*), and 8/9 subscales had ratios ≥ 5.0 ; the percent residual variance explained by the first component ranged from a high of 14.4% (*Coping*) to a low of 7.2% (*Psycho-Emotional*).

Reliability

Internal consistency—Cronbach's alpha is most appropriately used when the items measure different substantive areas within a single construct [50]. We wanted to measure our separate need dimensions with as few items as possible and took care to avoid artificially inflating alpha by adding items whose content represented only superficial changes in wording. The commonly accepted criteria for alpha are: $\alpha \geq 0.9$, excellent; $0.8 \leq \alpha < 0.9$, good; and $\alpha < 0.8$, acceptable [51]. Alpha for the 9 CCSS-NAQ subscales ranged from 0.94 (*Health System Concerns*) to 0.97 (*Survivor Care & Support*) (Table 3).

Person reliability—Person reliability in Rasch modeling is established by demonstrating a well-targeted pool of items and a sufficiently large spread of ability (i.e., need level) across the sample to demonstrate a hierarchy of ability on the construct being measured [41, 52]. The *person reliability index* is an indicator of the replicability of person ordering to be expected if the same sample were given a parallel set of items measuring the same construct. High person reliability (≥ 0.80) suggests that the scale will detect both low and high scorers and that these inferences will be consistent across other samples [41]. The items comprising the nine subscales reliably ordered participants in the sample relative to their need levels, as indicated by person-reliability estimates of 0.80–0.90 across the domains (Table 3). This index is similar in theory and interpretation to traditional measures of internal consistency but is slightly more conservative, as it removes extreme measures (i.e., zero or perfect scores) from the analysis and adjusts for the fact that data never fit the Rasch model perfectly [52].

Item reliability—The Rasch model provides an *item reliability index* to assess the replicability of item placement along the Rasch continuum. This index predicts whether the hierarchy of the items would remain stable if responded to by a different sample of the same size. For example, would “info about what causes cancer” (item INS43) remain less likely to be endorsed than “info about cancer recurrence” (item INS41) in a different sample? The item reliability index for the nine subscales ranged from 0.97 to 0.99, indicating a high degree of item stability (Table 3).

Test-retest reliability—Data for the short-term stability assessment were collected by mail. Test-retest intervals ranged from 2 to 28 weeks (mean = 5.9 weeks). Table 4 provides the test-retest correlations for those who returned their second questionnaire at 4, 5, 6, and 12 weeks, respectively. All of the nine subscales met the minimally acceptable test-retest correlation of 0.50 for group data across all of the intervals [53]; eight subscales had correlation coefficients ranging between 0.71 and 0.92 at four weeks. As the length of the

test interval increased from 4 to 12 weeks, the test-retest coefficient decreased for every subscale except *Health System Concerns*.

Item Analysis

Assessment of item fit—Item fit was analyzed by using mean-square statistics, graphical inspection of observed vs. expected item response curves, point-measure correlations between individual items and the total measure, and residual-based fit statistics [54]. Two mean-square ratios are typically used to determine how well the data fit a Rasch model: infit represents the information-weighted mean square residuals between observed and expected responses; outfit is similar to infit, but it is not weighted and is based on the conventional sum of squared standardized residuals, which makes the outfit statistic more sensitive to outliers. Bond and Fox [41] proposed criteria for acceptable and unacceptable model-data fit for clinical observation instruments (as opposed to clinical diagnosis instruments): infit and outfit statistics with a value near 1 are considered satisfactory, while values ≥ 1.7 (excess variation) or < 0.5 (insufficient variation) indicate a misfit. Item fit was assessed by subscale. Of 137 items, 135 fit the Rasch model. Infit values were 0.59–1.51 (Table 3). Outfit statistics showed a slightly wider range (0.48–2.29), and both of the misfitting items were on the *Surveillance* subscale. Although values < 0.5 demonstrate too little variation, these items often have high item-to-total correlations, contributing to the subscale's reliability. The low outfit value (0.48) suggests near identical ratings for survivors with low need levels vs. high need levels on the item "Need information about how screening tests are performed." As almost all survivors are relatively uninformed about screening procedures, this item might be endorsed independently of the survivor's overall need level. "Need information about screening tests based on my treatment history" had an outfit value of 2.29, indicating inconsistent performance (e.g., unexpectedly high or low need endorsement by a particular survivor); this item, too, is likely independent of the survivor's actual need status, as most survivors are unaware of their treatment-based risk status. While these two items may not discriminate as well as other items on the *Surveillance* subscale, they provide important information, and deleting either or both items impaired person and item reliability. These items were therefore retained in the subscale.

Point-measure correlations—Items with higher point-measure correlations (Table 3) are stronger indicators of the overall construct being measured. All of the point-measure correlations (0.53–0.91) were above the acceptable criterion of 0.50 [55].

Local independence—When scales fit the Rasch model, items can be assumed to possess local independence, meaning that if the underlying construct is held constant, any two items are independent of one another. Local independence was assessed by examining the correlations between item residuals for all possible pairs of items. Linacre [56] reported that a correlation that approaches 0.70 may indicate that a pair of items is duplicative or dominated by a shared factor. Two items on the *Fiscal Concerns* subscale had a residual correlation of 0.82: "Help paying for medical treatments" and "Help paying for physician or hospital costs." We removed one of these items from the pair and observed a correlation of 0.999 between the modified and original subscales [57]. Because unidimensionality of the subscale had been demonstrated, both items had acceptable infit, outfit, and PT-measure values, and the two items had related but distinctive content, we retained both items on the subscale.

Differential item functioning—When groups are heterogeneous, item scores can differ substantially between groups. Differential item functioning (DIF) refers to differences between two or more groups in the probability that an item will be endorsed, after adjustment for group differences in overall level of a given need. To test the invariance

assumptions for the items, we performed DIF analyses by income, education, and race. We did not perform DIF assessments for gender, diagnosis, and time since diagnosis, as we expected those variables to be strong covariates of the subscale measures [14, 58, 59]. The criteria for significantly different item functioning included: a) a significant summary χ^2 statistic when 3 or more groups were compared or a significant Mantel-Haenszel χ^2 with Bonferroni adjustment when two groups were compared; and b) a difference of 0.5 standard deviation units in item difficulty values between groups (DIF effect size). The latter measure was subscale-specific and was calculated by multiplying the SD of the total scale score by 0.5 [60, 61]. No items demonstrated DIF for race; however, 18 of 137 items demonstrated significant DIF (a P value ≤ 0.05 and a DIF contrast that exceeded the DIF effect size) as a function of education, income, or both.

To determine the impact of the 18 DIF items on the measures, we compared the DIF-adjusted subscale measure (all non-DIF items were anchored to their total sample values, independent of income and/or education, while the remaining DIF items retained their income and/or education-specific values) to the subscale measure not adjusted for DIF. DIF-adjusted and non-adjusted measures from each scale were cross-plotted with a regression line formed by predicting the DIF-adjusted measure based on its unadjusted counterpart. Deviations from 1.0 in correlation between the two measures, regression slopes of 1.0, and intercepts of 0.0 indicate the impact of DIF on the measure. In addition, root mean-square error (RMSE) was computed between DIF-adjusted and -unadjusted person measures for each subscale; RMSEs < 0.20 are indicative of good agreement. Using these procedures, we examined the impact of education ($<$ college vs. college grad) and income ($<$ \$60k vs. \$60K) DIF. Table 5 displays the correlation between the two measures, Root mean square error (RMSE), slope, and intercept (Y is the adjusted DIF, X is the unadjusted DIF). The slope deviated significantly from 1.00 only on the Fiscal Concerns subscale relative to income. For the remainder of the subscales showing DIF, only the intercept differed between the unadjusted and adjusted measures. We were able to remove two DIF items (“Fears about losing independence” and “loneliness”) from the *Psycho-Emotional* subscale without affecting the measure’s content or performance. Two items (“transportation to and from medical appointments/screenings” and “transportation for work or household activities”) on the *Fiscal Concerns* subscale were evaluated for removal; neither could be removed without jeopardizing the Rasch fit criteria for other items; they were therefore retained on the subscale. Given an intercept of 0.22, fiscal concern needs could be very slightly overestimated among survivors with higher incomes and very slightly underestimated among those with lower incomes.

Co-variation of Health-related Needs by Demographic, Disease, and Treatment Exposure Variables

A number of factors were found to be significant covariates of the subscale means (Table 6). Age ≥ 40 was associated with higher need levels on all nine subscales. Female gender was associated with higher-level needs on all subscales except *Fiscal Concerns*. Having less than a college education was associated with higher need levels on all subscales except *Psycho-Emotional*, *Cancer-related Health Information* and *Surveillance*. Annual income $\leq \$59,999$ was associated with higher need levels on all subscales except *Cancer-related Health Information*. Survivors not living with a spouse or partner reported higher-level needs than did other survivors on every subscale except *Cancer-related Health Information* and *Fiscal Concerns*. Older age at diagnosis (10–14 and 15–20 years vs. ≤ 4 and 5–9 years) was associated with higher need levels. With the exception of the *Survivor Care and Support* subscale, survivors of Wilms tumor reported lower need levels than did survivors of other malignancies. In contrast, survivors of a bone malignancy or Hodgkin lymphoma reported higher-level needs across most measures. Treatment exposures were not associated with

differing need levels on the *Fiscal Concerns* or *Relationships* subscales (Table 6). Exposure to radiation alone or in combination with chemotherapy accounted for higher need levels on all seven remaining subscales compared to chemotherapy or surgery only.

DISCUSSION

We have described the construction and evaluation of a new self-report instrument for assessment of the health-related needs of adult survivors of childhood cancer. The original instrument contained 190 items within 17 hypothesized domains. Using both classical test theory and item response theory, we were able to streamline the instrument to 135 items distributed over 9 subscale domains. Fifty-three items related to nutrition, sexuality, services (adoption, infertility, legal, childcare), fitness, and spirituality were dropped; these items demonstrated poor item-fit statistics and low subscale person reliability. These topics may be better assessed by instruments geared specifically to those content areas rather than as a component of a general needs assessment instrument. Two additional items from the *Psycho-Emotional* subscale were eliminated because of differential item functioning.

The low response rate of 39% mirrors that of other recent childhood cancer survivor studies [62]. More than half of the non-respondents were male, again consistent with previous CCSS reports [63]. Our attempt to over represent minority populations was partially successful. Hispanic CCSS participants constitute 5.6% of the CCSS cohort [64] and 5.8% of the sample in this study. Whereas African-Americans represent 5.6% of the CCSS cohort [64], only 2.6% were recruited as participants in this study. Members of the CCSS cohort are relatively young and highly mobile; moreover they have been extensively studied with the recurrent CCSS follow-up studies and several ancillary studies. Some participants were invited to participate in more than one ancillary study at the time of our survey. Despite our strong appeals relative to saliency of the study, extensive recruitment efforts, and generous remuneration, the length of our survey instrument and requests for participation in multiple studies simultaneously may have had a significant impact on our participation rate. Expanding recruitment beyond the CCSS cohort, including other research networks (e.g., The Childhood Cancer Research Network (CCRN) Children's Oncology Group) and childhood cancer support groups, recruiting through web-based media, offering the option to respond to the questionnaire electronically, and oversampling minorities and low income/education survivors at a greater than 2:1 ratio are strategies we will embrace in future studies. We likely will include \$1.00 with a mailed survey and provide the remainder of the remuneration when the survey is returned; this strategy is apparently more successful in increasing response rates than is payment only after the survey has been returned [65].

The construct validity, reliability, and unidimensionality of the CCSS-NAQ's nine subscales were well demonstrated. Test-retest correlations were high for eight of the nine subscales at four weeks, and declined with increasing assessment intervals. While acceptable, the *Health System Concerns* subscale demonstrated lower test-retest correlations than did any other subscale at four and five weeks. These test-retest correlations were higher at 6 and 12 weeks, when other subscales had lower correlations. This subscale largely addresses content specific to provider interaction. While only speculation, there could be multiple confounders that influence increasing correlations over time (e.g., more frequent contact with providers, increased illness experience, new providers). Additional large-scale test-retest assessments with greater control of the time interval will be conducted to more fully inform this finding.

Survivors clustered at the lower need levels on subscales that addressed more focused needs (e.g., *Psycho-Emotional*, *General Health*, *Coping*). Given the relatively young median age of the cohort (39 years), most of these survivors would not be expected to report high-level needs on these subscales. Our ultimate goals for this instrument include 1) longitudinal

assessment of changes in needs as survivors age, (2) characterization of needs related to more severe late effects, and 3) need characterization of survivors with high-risk treatment exposures. We expect the less frequently endorsed items in the CCSS-NAQ to be more fully utilized in these segments of the target population.

Two items functioned differentially on the *Fiscal Concerns* subscale, depending on the survivor's income. Using income-specific item calibrations for these items will reduce any impact of DIF and increase the measure's precision.

Adult survivors of CNS pediatric malignancies are at high risk for long-term morbidity and mortality. They have an increased risk of developing new endocrine, neurological, or sensory complications five or more years after diagnosis; neurocognitive impairment is high and these survivors have lower rates of employment and marriage [66]. Given their history, we might expect these survivors to report higher-level needs than survivors with other pediatric malignancy diagnoses. However, their need levels were below those of survivors with other diagnoses. Because of their risks, this group of survivors need and often receive high-quality long-term follow-up in specialized cancer centers. During treatment and follow-up, their progress is carefully monitored, their multiple needs anticipated, and interventions to modify risks are implemented. Therefore, this group of survivors, in contrast to others who are less frequently monitored, may potentially be in an optimal position to have their needs assessed and met. We deliberately excluded survivors who were not cognitively capable of self-report; this exclusion eliminated some of the more severely cognitively impaired CNS survivors who would likely have higher need levels. Subsequent studies will look at the multiple diagnoses and their need levels by time since diagnosis, treatment exposures, and specific need items endorsed to further qualify these findings.

Our findings that Wilms survivors reported lower need levels than did survivors of bone of Hodgkin lymphoma are consistent with clinical expectations. Wilms survivors are at considerably lower risk of delayed treatment complications than are survivors of bone tumor or Hodgkin lymphoma [14, 58, 59, 67, 68].

Not surprising, exposure to radiation or radiation together with chemotherapy was associated with higher self-reported need levels on all subscales except *Fiscal Concerns* and *Relationships*. Radiation therapy has been associated with increased mortality risk, second neoplasms, obesity, and pulmonary, cardiac and thyroid dysfunction as well as an increased overall risk for chronic health conditions [69]. These sequelae would logically contribute to perceptions of increased needs related to general health, psycho-emotional and coping concerns, health information, surveillance and screening, and survivor care and support. Future studies will look at treatment exposures together with other likely covariates of higher need levels as they relate to overall subscale scores and individual items within each need domain.

It is imperative that we understand and meet survivors' self-defined needs that may affect their quality of life and may modify treatment-related late effects; the urgency of this challenge is increased by the aging of this population. With additional validity support, CCSS-NAQ has the potential to inform risk-based care for survivors by: 1) documenting the needs of aging childhood cancer survivors; b) identifying the extent to which these needs are met; c) comparing and contrasting the extent of unmet needs in different segments of the survivor population; d) tracking how survivors' needs change with aging; and e) assisting the health care system to be proactive in developing models of survivor care to address these needs. CCSS-NAQ can potentially inform preventive screening strategies and prospective interventions. The instrument can be used in whole or by selected subscales to: 1) triage survivors to appropriate services; 2) plan a comprehensive risk-based approach in "after

treatment” clinics in cancer care centers; and 3) serve as a long-term follow-up care resource for both provider and survivor in primary care settings once the survivor transitions to community care.

LIMITATIONS

Several limitations are appreciated in the study. The sample is racially/ethnically skewed, well educated, and more than half of the non-respondents were male. Moreover, while the CCSS population is a large and heterogeneous cohort of 5-year survivors, our results may not be generalizable to all childhood cancer survivors. Future studies must incorporate strategies to assure greater potential for generalizability.

There is some potential for item selection bias. Our expert panel selected some previously tested items from existing instrumentation over others when they felt the wording or context to be better suited to childhood cancer survivors. Our study team and study methods, however, were strengths in potentially moderating item selection bias: 1) collectively the panel has over 70 years of clinical and research experience in providing care to survivors of pediatric malignancies; 2) we made the decision to err on the side of defining our domains too broadly, rather than excluding domains that potentially could be important; 3) we relied on previously developed and tested items not developed by the study team; 4) we subjected all items to differential analysis in an effort to assure that items were not racially/ethnically or socio-economically biased; 5) we included open-ended questions on the questionnaire that allowed survivors to identify any health-related needs that they felt were not addressed on the questionnaire.

CONCLUSION

Our initial analyses indicate that CCSS-NAQ is construct valid and reliable, discriminates between survivors with differing need levels, and differentiates survivors' needs relative to demographic, disease, and treatment exposure variables. Future studies will 1) further establish the predictive validity of the instrument, 2) establish norms and thresholds for each subscale, and 3) longitudinally track survivors' needs within different age, diagnosis, and specific late-effects cohorts.

Acknowledgments

SUPPORT: R21 CA142921 (CL Cox, PI), U24 CA55727 (LL Robison, PI), and CA21765 (RJ Gilbertson, PI) of the National Institutes of Health, and the American Lebanese Syrian Associated Charities (ALSAC).

References

1. Hewitt, M.; Weiner, SL.; Simone, JV. Childhood Cancer Survivorship: improving care and quality of life. Washington, DC: National Academies Press; 2003.
2. Ries, LAG.; Melbert, D.; Krapcho, M.; Mariotto, A.; Miller, BA.; Feuer, EJ., et al. SEER cancer statistics review 1975–2004. Vol. 2007. Bethesda, MD: National Cancer Institute; 2007. based on November 2006 SEER data submission, posted to the SEER Web site http://seer.cancer.gov/csr/1975_2004/
3. Mertens AC, Liu Q, Neglia JP, Wasilewski K, Leisenring W, Armstrong GT, et al. Cause-specific late mortality among 5-year survivors of childhood cancer: the Childhood Cancer Survivor Study. J Natl Cancer Inst. 2008; 100:1368–79. [PubMed: 18812549]
4. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Chronic health conditions in adult survivors of childhood cancer. N Engl J Med. 2006; 355:1572–82. [PubMed: 17035650]

5. Hewitt, M.; Greenfield, S.; Stovall, E. Committee on Cancer Survivorship: Improving care and quality of life: Institute of Medicine and National Research Council. Washington, DC: National Academies Press; 2005. p. 187-321.
6. Rowland JH, Bellizzi KM. Cancer survivors and survivorship research: a reflection on today's successes and tomorrow's challenges. *Hematol Oncol Clin North Am.* 2008; 22:181–200. v. [PubMed: 18395144]
7. National Audit Office. Tackling Cancer: Improving the patient journey. London: The Stationary Office; 2005.
8. National Cancer Alliance. Patient-centred Cancer Services? What patients say. Oxford: NCA; 1996.
9. Earle EA, Davies H, Greenfield D, Ross R, Eiser C. Follow-up care for childhood cancer survivors: A focus group analysis. *Eur J Cancer.* 2005; 41:2882–6. [PubMed: 16275059]
10. Nagel K, Eves M, Waterhouse L, Alyman C, Posgate S, Jamieson J, et al. The development of an off-therapy needs questionnaire and protocol for survivors of childhood cancer. *J Pediatr Oncol Nurs.* 2002; 9:229–33. [PubMed: 12444575]
11. Trask CL, Welch JJ, Manley P, Jelalian E, Schwartz CL. Parental needs for information related to neurocognitive late effects from pediatric cancer and its treatment. *Pediatr Blood Cancer.* 2009; 52:273–9. [PubMed: 18985741]
12. Arvidson J, Söderhäll S, Eksborg S, Björk O, Krueger A. Medical follow-up visits in adults 5–25 years after treatment for childhood acute leukaemia, lymphoma or Wilms' tumor. *Acta Paediatr.* 2006; 95:922–8. [PubMed: 16882563]
13. Hovén E, Lannering B, Gustafsson G, Boman KK. The met and unmet health care needs of adult survivors of childhood central nervous system tumors. *Cancer.* 2011; 117:4294–4303. [PubMed: 21387277]
14. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Childhood Cancer Survivor Study. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med.* 2006; 355:1572–82. [PubMed: 17035650]
15. Galloway S, Graydon J, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, et al. Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *J Adv Nurs.* 1997; 25:1175–83. [PubMed: 9181414]
16. Graydon J, Galloway S, Palmer-Wickham S, Harrison D, Rich-van der Bij L, West P, et al. Information needs of women during early treatment for breast cancer. *J Adv Nurs.* 1997; 26:59–64. [PubMed: 9231278]
17. Gray RE, Fitch M, Greenberg M, Hampson A, Doherty M, Labrecque M. The information needs of well, longer-term survivors of breast cancer. *Patient Educ Couns.* 1998; 33:245–55. [PubMed: 9731162]
18. Ganz PA, Rofessart J, Polinsky ML, Schag CC, Heinrich RL. A comprehensive approach to the assessment of cancer patients' rehabilitation needs: the Cancer Inventory of Problem Situations and a companion interview. *J Psychosoc Oncol.* 1986; 4:27–42.
19. Ganz PA, Schag CC, Polinsky ML, Heinrich RL, Flack VF. Rehabilitation needs and breast cancer: the first month after primary therapy. *Breast Cancer Res Treat.* 1987; 10:243–53. [PubMed: 3447644]
20. Meyerowitz, BE.; Heinrich, RL.; Schag, CC. A competency-based approach to coping with cancer. In: Burish, TG.; Bradley, L., editors. *Coping with Chronic Disease: Research and Applications.* New York: New York Academic Press; 1983. p. 137-58.
21. Schag CC, Heinrich RL, Ganz PA. Cancer Inventory of Problem Situations: An instrument for assessing cancer patients' rehabilitation needs. *J Psychosoc Oncol.* 1983; 1:11–24.
22. Pearce NJ, Sanson-Fisher R, Campbell HS. Measuring quality of life in cancer survivors: A methodological review of existing scales. *Psychooncology.* 2008; 17:629–40. [PubMed: 17973235]
23. Girgis A, Boyes A, Sanson-Fisher RW, Burrows S. Perceived needs of women diagnosed with breast cancer: rural versus urban location. *Aust N Z J Public Health.* 2000; 24:166–73. [PubMed: 10790936]

24. Coyle N, Goldstein ML, Passik S, Fishman B, Portenoy R. Development and validation of a patient needs assessment tool (PNAT) for oncology clinicians. *Cancer Nurs.* 1996; 19:81–92. [PubMed: 8635168]
25. Mesters I, van den Borne B, De Boer M, Pruyn J. Measuring information needs among cancer patients. *Patient Educ Couns.* 2001; 43:253–62. [PubMed: 11384823]
26. Derdiarian AK. Informational needs of recently diagnosed cancer patients. *Nurs Res.* 1986; 35:276–81. [PubMed: 3638607]
27. Denger LF, Davison BJ, Sloan JA, Mueller B. Development of a scale to measure information needs in cancer care. *J Nurs Meas.* 1998; 6:137–53. [PubMed: 10028780]
28. Streiner, DL.; Norman, GR. *Health measurement scales: A practical guide to their development and use.* 3. Oxford: Oxford University Press; 2003.
29. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess.* 1998; 2:1–74. [PubMed: 10103353]
30. Kirsch, I.; Jungeblut, A.; Jenkins, L.; Kolstad, A. *Adult literacy in America: a first look at the findings of the Adult Literacy Survey.* 3. Washington, DC: US Department of Education; 2002.
31. Childhood Cancer Survivor Study. St. Jude Children's Research Hospital; <http://ccss.stjude.org/documents/questionnaires>
32. Robison LL, Mertens AC, Boice JD, Breslow NE, Donaldson SS, Green DM, et al. Study design and cohort characteristics of the Childhood Cancer Survivor Study: A multi-institutional collaborative project. *Med Pediatr Oncol.* 2002; 38:229–39. [PubMed: 11920786]
33. Robison LL, Armstrong GT, Boice JD, Chow EJ, Davies SM, Donaldson SS, et al. The Childhood Cancer Survivor Study: a National Cancer Institute-supported resource for outcome and intervention research. *J Clin Oncol.* 2009; 27:2308–18. [PubMed: 19364948]
34. Greenlee RT, Murray T, Bolden S, Wingo PA. Cancer statistics, 2000. *CA Cancer J Clin.* 2000; 50:7–33. [PubMed: 10735013]
35. Retinoblastoma Follow-up Study. U.S. National Institutes of Health; <http://rbstudy.cancer.gov/faqs.html>
36. Hatcher, L. *A step by step approach to using the SAS system for factor analysis and structural equation modeling.* Cary, NC: SAS Institute; 1994.
37. Hulin CL, Lissak RI, Drasgow F. Recovery of two- and three-parameter logistic item characteristic curves: A Monte Carlo Study. *Applied Psychological Measurement.* 1982; 6:249–60.
38. Chernesky RH, Gutheil IA. Rethinking needs assessment in planning services for older adults. *J Gerontol Soc Work.* 2008; 51:109–25. [PubMed: 18826071]
39. Centers for Disease Control and Prevention. 2004 National Health Interview Survey (NHIS): Public use data release, US Department of Health and Human Services. Division of Health Interview Statistics, National Center for Health Statistics; Hyattsville, MD: 2005. Available from URL: <http://www.cdc.gov/nchs/data/nhis/srvydesc.pdf>
40. Rasch, G. *Probabilistic models for some intelligence and attainment tests.* Copenhagen, Denmark: Danmarks Paedagogiske Institut; 1960.
41. Bond, TG.; Fox, CM. *Applying the Rasch Model: Fundamental measurement in the human sciences.* 2. New York: Routledge Publishing; 2007.
42. Hayes RD, Morales LS, Reise SP. Item response theory and health outcomes measurement in the 21st century. *Med Care.* 2000; 38:1128–42.
43. Reeve, BB.; Fayers, P. Applying item response theory modeling for evaluating questionnaire item and scale properties. In: Fayers, P.; Hays, RD., editors. *Assessing quality of life in clinical trials: methods of practice.* 2. New York: Oxford University Press; 2005. p. 55-73.
44. Sharkness J, DeAngelo L. Measuring student involvement: A comparison of classical test theory and item response theory in the construction of scales from student surveys. *Res High Educ.* 2011; 52:480–507.
45. Hu L, Bentler P. Cutoff criteria for fit indices in covariance structure analysis; conventional criteria versus new alternatives. *Structural Equation Modeling.* 1999; 6:1–55.
46. Smith EV. Evidence for the reliability of measures and validity of measure interpretations: A Rasch model perspective. *J Appl Meas.* 2001; 2:281–311. [PubMed: 12011511]

47. Conrad, KJ.; Conrad, KM.; Dennis, ML., et al. Validation of the Crime and Violence Scale (CVS) to the Rasch measurement model, GAIN Methods Report 1.2. Chicago: Chestnut Health Systems; 2011. Available from URL: http://www.chestnut.org/li/gain/psychometric_reports/Conrad_et_al_2011_CVS_Rasch_Report.pdf
48. Conrad KJ, Riley BB, Conrad KM, Chan YF, Dennis ML. Validation of the crime and violence scale against the Rasch measurement model including difference by gender, race, and age. *Eval Rev.* 2010; 34:83–115. [PubMed: 20233998]
49. Smith EV. Detecting and evaluating the impact of multidimensionality using item fit statistics and principal component analysis of residuals. *J Appl Meas.* 2002; 3:205–31. [PubMed: 12011501]
50. Zinbarg R, Yovel I, Revelle W, McDonald R. Estimating generalizability to a universe of indicators that all have an attribute in common: A comparison of estimators for omega. *Appl Psych Meas.* 2006; 30:121–44.
51. Cronbach LI, Shavelson RJ. My current thoughts on coefficient alpha and successor procedures. *Educ Psycho Meas.* 2004; 64:391–418.
52. Fox CM, Jones JA. Uses of Rasch modeling in counseling psychology research. *J Couns Psychol.* 1998; 45:30–45.
53. Helmstadter, GC. Principles of psychological measurement. New York: Appleton-Century-Crofts; 1964.
54. Smith EV. Evidence for the reliability of measures and validity of measure interpretations: A Rasch model perspective. *J Appl Meas.* 2001; 2:281–311. [PubMed: 12011511]
55. Linacre JM. Data variance explained by measures. *Rasch Measurement Transactions.* 2006; 20:1045.
56. Linacre JM. Investigating judge local independence. *Rasch Measurement Transactions.* 1997; 11:546–7.
57. Linacre JM. More objections to the Rasch Model. *Rasch Measurement Transactions.* 2010; 24:1298–9.
58. Hudson MM, Mertens AC, Yutaka Y, Hobbie W, Chen H, Gurney JG, et al. Health status of adult long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *JAMA.* 2003; 290:1583–92. [PubMed: 14506117]
59. Friedman DL, Whitton J, Leisenring W, Mertens AC, Hammond S, Stovall M, et al. Subsequent neoplasms in 5-year survivors of childhood cancer: The Childhood Cancer Survivor Study. *JNCI.* 2010; 102:1083–95. [PubMed: 20634481]
60. Norman GR, Sloan JA, Wyrich KW. Interpretation of changes in health-related quality of life: The remarkable universality of half a standard deviation. *Med Care.* 2003; 41:582–92. [PubMed: 12719681]
61. Conrad KJ, Dennis ML, Bezruckzo N, Funk RR, Riley BB. Substance use disorder symptoms: evidence of differential item functioning by age. *J Appl Meas.* 2007; 8:373–87. [PubMed: 18250524]
62. Harlan LC, Lynch CF, Keegan TH, Hamilton AS, Wu XC, Kato I, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *J Cancer Surv.* 2011; 5:305–14.
63. Cox CL, Hudson MM, Mertens A, Oeffinger K, Whitton J, Montgomery M, et al. Medical screening participation among childhood cancer survivors. *Arch Intern Med.* 2009; 169:454–62. [PubMed: 19273775]
64. Castellino SM, Geiger AM, Mertens AC, Leisenring WM, Tooze JA, Goodman P, et al. Morbidity and mortality in long-term survivors of Hodgkin lymphoma: a report from the Childhood Cancer Survivor Study. *Blood.* 2011; 117:1806–16. [PubMed: 21037086]
65. Porter, SR. Raising response rates: What works? New directions for institutional research. Wiley Periodicals, Inc; 2004. p. 5-21.
66. Armstrong GT, Liu Q, Yasui Y, Huang S, Ness KK, Leisenring W, et al. Long-term outcomes among adult survivors of childhood central nervous system malignancies in the Childhood Cancer Survivor Study. *J Natl Cancer Inst.* 2009; 101:946–58. [PubMed: 19535780]

67. Nathan PC, Ness KK, Greenberg ML, Hudson MM, Wolden S, Davidoff A, et al. Health-related quality of life in adult survivors of childhood Wilms tumor or neuroblastoma: A report from the Childhood Cancer Survivor Study. *Pediatr Blood Cancer*. 2007; 49:704–15. [PubMed: 16830322]
68. Castellino SM, Casillas J, Hudson MM, Mertens AC, Whitton J, Brooks SL, et al. Minority adult survivors of childhood cancer: A comparison of long-term outcomes, health care utilization, and health-related behaviors from the Childhood Cancer Survivor Study. *JCO*. 2005; 23:6499–507.
69. Armstrong GT, Stovall M, Robison LL. Long-term effects of radiation exposure among adult survivors of childhood cancer: results from the Childhood Cancer Survivor Study. *Radiat Res*. 2010; 174:840–50. [PubMed: 21128808]

FIG. 1.
Flow chart of the study sample

Table 1

Descriptive Summary of the Sample (N=1178)

	No.	% of Total
Current age		
25–30 years	161	13.67
31–41 years	540	45.84
42 years	477	40.49
	<i>M</i> = 39.7	<i>SD</i> = 7.7
Sex		
Male	461	39.13
Female	717	60.87
Race		
African American	30	2.55
Caucasian	1051	89.22
Hispanic	68	5.77
Other	29	2.46
Relationship Status		
Married/living with partner	746	63.33
Single/divorced/widowed/separated	431	36.59
Data missing	1	0.08
Residence		
Urban	997	84.63
Rural	181	15.37
Diagnosis		
Leukemia	398	33.79
CNS tumor	158	13.41
Hodgkin lymphoma	149	12.65
Non-Hodgkin lymphoma	86	7.30
Wilms tumor	121	10.27
Neuroblastoma	74	6.28
Soft tissue sarcoma	107	9.08
Bone tumor	85	7.22
Treatment Exposure		
Chemotherapy (no radiation)	289	24.53
Radiation (no chemotherapy)	156	13.24
Surgery only	100	8.49
Chemotherapy + radiation	561	47.62
No chemotherapy/radiation/surgery	2	0.17
Unknown	70	5.94

	No.	% of Total
Years Since Diagnosis		
<28.16 years	572	48.90
28.16 years	602	51.10
Age at Diagnosis		
0–4 years	449	38.12
5–9 years	268	22.75
10–14 years	243	20.63
15–20 years	218	18.51
Economic Status		
Highest household education		
No high school diploma or GED	5	0.42
High school diploma or GED	87	7.39
Some college; no bachelor's degree	173	14.69
Bachelor's degree or higher	855	72.58
Other	54	4.58
Data missing	4	0.34
Household income		
<\$20,000/year	95	8.06
\$20,000 \$40,000/year	164	13.92
\$40,000 \$60,000/year	197	16.72
\$60,000 \$80,000/year	186	15.79
\$80,000 \$100,000/year	117	9.93
\$100,000/year	308	26.15
Data missing	111	9.43
Household Membership		
	Mean	SD
No. adults	2.16	1.88
No. children	0.87	1.10
No. sick adults requiring care	0.07	0.32
No. sick children requiring care	0.03	0.25
Employment Status		
Unemployed	76	6.45
Employed		
Full-time	724	61.46
Part-time	132	11.21
Health Insurance		
Yes	1067	90.58
No	95	8.06
Data missing	16	1.36

	No.	% of Total
Primary Care		
Yes	1107	93.97
No	49	4.16
Data missing	22	1.87

Table 2

Comparison of the 17 Originally Hypothesized and the 9 Final Health-related Need Domains

Originally Hypothesized Domains	Final Domains
Psychological/emotional	Psychological/emotional
Health system concerns	Health system concerns
Cancer-related health information	Cancer-related health information
Physical and daily living	General health
Survivor care and support	Survivor care and support
Surveillance	Surveillance
Coping	Coping
Fiscal concerns	Fiscal concerns
Relationships	Relationships
Sexuality	All items eliminated in Rasch analysis
Life perspective	All items moved to <i>Coping</i> subscale
Services	All items eliminated in Rasch analysis
Transportation	All items moved to <i>Fiscal Concerns</i> subscale
Employment	All items moved to <i>Fiscal Concerns</i> subscale
Spiritual	All items eliminated in Rasch analysis
Nutrition	All items eliminated in Rasch analysis
Insurance	Selected items moved to <i>Fiscal Concerns</i> subscale

Table 3

CCSS-NAQ Subscales, Items, and Fit Statistics

Subscales (α) and Items		Rasch Item Calibrations and Fit Statistics					
Abbreviated Items	Item ID	Infit	Outfit	PT-Measure Correlation	Person Reliability	Item Reliability	Separation Index
PSYCHO-EMOTIONAL ($\alpha=0.96$)					0.88	0.99	2.70
Help dealing with worry	INS7	0.80	0.78	0.82			
Help dealing with uncertainty about the future	INS5	1.13	1.29	0.76			
Help dealing with anxiety	INS6	0.90	0.87	0.81			
Help with reducing stress in life	INS23	1.05	1.10	0.77			
Help dealing with feeling down or depressed	INS9	0.97	0.94	0.79			
Help dealing with feeling very nervous, afraid, or tense	INS8	0.86	0.80	0.79			
Help feeling calm and peaceful	INS10	0.75	0.76	0.80			
Help maintaining a positive outlook	INS19	0.81	0.82	0.77			
Help dealing with fears about physical disability or deterioration	INS16	1.24	1.45	0.69			
Help dealing with feeling angry	INS11	0.92	0.85	0.75			
Help with loss of control over emotions	INS24	1.04	1.03	0.72			
Help dealing with fears about pain	INS3	1.34	1.50	0.66			
Help feeling in control of my situation	INS17	0.85	0.81	0.75			
Help finding meaning in this experience	INS20	1.02	1.13	0.70			
Help dealing with changes to my usual routine and lifestyle	INS22	1.21	1.34	0.67			
Help making the most of my time	INS18	1.00	0.91	0.69			
Help dealing with feeling bored or useless	INS14	1.12	1.07	0.66			
HEALTH SYSTEM CONCERNS ($\alpha=0.94$)					0.80	0.98	2.02
Information about important aspects of my after-cancer care	INS28	1.24	1.33	0.77			
My doctors to talk to each other to coordinate my care	INS34	0.85	0.84	0.83			
One health care provider with whom I could talk about my health	INS33	0.88	0.83	0.82			
Help to know how to give input to my medical team	INS35	0.73	0.66	0.83			
Information about whom to call for help	INS39	1.33	1.55	0.71			
Choices about when to go in for check-ups in order to manage my health	INS32	0.86	0.87	0.79			
My complaints about my care heard and addressed	INS36	0.85	0.81	0.80			

Subscales (α) and Items		Rasch Item Calibrations and Fit Statistics						
Abbreviated Items	Item ID	Infit	Outfit	PT-Measure Correlation	Person Reliability	Item Reliability	Separation Index	
To be treated like a person not just another case	INS31	0.91	0.91	0.78				
Help finding access to professional counseling	INS30	1.13	1.19	0.74				
Information about support groups in my area	INS29	1.21	1.18	0.71				
CANCER-RELATED HEALTH INFORMATION ($\alpha=0.96$)					0.85	0.98	2.38	
Information about the late effects of my cancer therapy	INS44	1.05	1.07	0.83				
Information about how cancer affected my body	INS42	1.00	0.98	0.84				
Information about which organ systems may have been affected by my cancer treatment	INS50	0.76	0.74	0.87				
Information about specific diseases that can result from cancer therapy	INS46	0.81	0.76	0.86				
Information about what I can do to reduce my chances of developing late effects	INS47	0.82	0.78	0.86				
Information about how cancer will affect my life	INS51	0.97	0.98	0.83				
Information about cancer recurrence	INS41	1.14	1.19	0.80				
Information about my treatments or medications	INS48	0.97	0.93	0.82				
Information about what symptoms to report to the doctor or nurse	INS45	1.02	1.09	0.80				
Information about what causes cancer	INS43	1.19	1.31	0.78				
Information about my test results as soon as possible	INS49	1.23	1.22	0.77				
GENERAL HEALTH ($\alpha=0.95$)					0.84	0.99	2.29	
Help with feeling tired	INS59	1.14	1.26	0.78				
Help with lack of pep	INS58	1.07	1.13	0.77				
Help improving overall health	INS72	0.99	0.98	0.78				
Help with managing late effects of cancer	INS75	1.49	1.73	0.70				
Help feeling as healthy as other people	INS73	0.89	0.93	0.79				
Help maintaining overall health	INS71	0.90	0.86	0.77				
Help with feeling unwell a lot of the time	INS60	0.94	0.94	0.75				
Help accomplishing what I would like to because of physical health	INS78	0.81	0.68	0.74				
Help performing work or other daily activities because of physical health	INS76	0.79	0.70	0.73				
Help accomplishing what I would like to because of emotional health	INS79	1.05	1.27	0.66				
Help with continuing usual hobbies or sports	INS74	1.11	1.31	0.65				

Subscales (α) and Items		Rasch Item Calibrations and Fit Statistics						
Abbreviated Items	Item ID	Infit	Outfit	PT-Measure Correlation	Person Reliability	Item Reliability	Separation Index	
Help with doing the things that I used to do	INS63	0.92	0.78	0.69				
Help performing work or other daily activities because of emotional problems	INS77	1.04	1.03	0.66				
Help with work around the home	INS62	0.97	0.85	0.67				
Help climbing one flight of stairs	INS66	1.02	0.92	0.63				
Help with preparing meals or doing light housework or yard work	INS65	0.99	0.77	0.62				
SURVIVOR CARE and SUPPORT ($\alpha=0.97$)					0.90	0.98	3.01	
To be able to see the specialists I need/want to see	INS82	1.24	1.34	0.80				
My physician to help me understand how to reduce my late effects risks	INS92	1.51	1.64	0.76				
To know whom to call if I have questions	INS87	1.00	1.04	0.82				
Health care providers to acknowledge and show sensitivity to my feelings and emotional needs	INS81	1.12	1.15	0.79				
To have my physician understand my points of view	INS89	0.77	0.74	0.84				
My physician to answer my questions fully and carefully	INS95	0.81	0.76	0.83				
To know how to ask my physician to provide me with choices/options	INS88	0.86	0.86	0.82				
Reassurance by medical staff that the way I feel is normal	INS80	1.30	1.48	0.75				
To know that the medical staff is being honest	INS86	0.84	0.76	0.82				
To share my feelings with my physician	INS99	0.89	0.95	0.80				
My physician to care about me as a person	INS97	0.85	0.85	0.81				
My physician to encourage me to ask questions	INS93	1.01	1.01	0.78				
My physician to listen to how I would like to do things	INS96	0.85	0.78	0.80				
To secure more timely clinic appointments	INS83	1.19	1.14	0.75				
Someone to respond to my requests for medical help	INS84	0.93	0.89	0.78				
More say in decisions about my medical treatment	INS85	1.00	0.91	0.77				
My physician to understand how I see things before suggesting a new way to do things	INS98	0.83	0.73	0.79				
To have more trust in my physician	INS94	1.05	1.01	0.75				
My physician to have more confidence in my ability to make changes that are good for my health	INS90	0.92	0.96	0.73				
My physician to be more accepting of me	INS91	0.98	0.88	0.71				

Subscales (α) and Items	Item ID	Rasch Item Calibrations and Fit Statistics					
		Infit	Outfit	PT-Measure Correlation	Person Reliability	Item Reliability	Separation Index
Abbreviated Items							
SURVEILLANCE ($\alpha=0.96$)					0.83	0.99	2.19
Information about what screening tests I need based on my treatment history	INS107	1.50	2.29	0.81			
Information about which tests will help detect late effects of treatment	INS113	1.28	1.36	0.85			
Information about why screening tests need to be performed	INS112	0.77	0.65	0.90			
Information about how screening tests are performed	INS111	0.59	0.48	0.90			
Information about how I will feel during screening tests (e.g., bone scan, ECHO)	INS108	0.85	0.79	0.87			
Information on how to prepare for screening tests	INS109	0.68	0.65	0.89			
Information about how I will feel after screening tests	INS110	0.63	0.51	0.89			
Help with responsibilities so that I can participate in the recommended health screenings	INS114	1.44	1.27	0.80			
Realistic information about how much time screening tests will take	INS115	0.92	0.98	0.85			
COPING ($\alpha=0.95$)					0.80	0.97	2.00
Emotional support	INS121	0.81	0.86	0.82			
Opportunity to talk with someone who understands/been through similar experience	INS119	0.91	0.90	0.81			
To talk to other people about cancer	INS120	1.02	1.07	0.79			
Help coping with unpredictability of future	INS122	0.88	0.87	0.81			
Help with body image issues	INS116	1.38	1.56	0.72			
Help adjusting to changes in my body	INS117	1.01	0.99	0.78			
Making decisions about my life	INS151	0.93	0.98	0.75			
Help dealing with feeling loss of control over life	INS150	0.97	0.96	0.75			
Help making sense/meaning of my illness	INS154	1.04	1.07	0.73			
Help moving on with my life	INS153	0.98	0.93	0.75			
Help trying to make my life count	INS152	1.00	1.02	0.74			
Help dealing with changes in how feel as man/woman	INS118	1.11	1.02	0.70			
FISCAL CONCERNS ($\alpha=0.96$)					0.86	0.99	2.52
Insurance coverage for my other medical expenses	INS185	0.96	0.97	0.79			
Insurance coverage for my medications	INS184	0.99	1.02	0.77			

Subscales (α) and Items		Rasch Item Calibrations and Fit Statistics						
Abbreviated Items	Item ID	Infit	Outfit	PT-Measure Correlation	Person Reliability	Item Reliability	Separation Index	
Help understanding my health insurance coverage	INS186	1.08	1.19	0.75				
Help with concerns about my financial situation	INS124	0.96	1.09	0.76				
Help paying for physician or hospital costs	INS127	0.71	0.63	0.80				
Help paying for medical treatments	INS126	0.76	0.70	0.79				
Help paying for prescription medications	INS125	0.77	0.71	0.78				
Help paying for medical screenings	INS131	0.82	0.76	0.77				
Help meeting my basic living expenses	INS128	0.83	0.76	0.76				
Help with payments for care denied by my insurance carrier	INS188	1.18	1.36	0.69				
Help dealing with extra expenses because of cancer	INS129	0.91	0.79	0.74				
Help completing insurance forms	INS187	1.00	1.06	0.71				
Help dealing with reduced income because of cancer	INS130	0.90	0.72	0.71				
Assistance with disability or social security	INS189	1.29	1.70	0.62				
Help with being unable to work because of pain	INS172	1.28	1.60	0.57				
Transportation to and from medical appointments/screenings	INS163	1.11	1.60	0.58				
Help keeping my job	INS168	1.25	1.10	0.57				
Help with difficulty working	INS170	1.17	1.11	0.58				
Help making the same salary	INS169	1.12	1.05	0.59				
Help with at-work concerns	INS171	1.09	1.25	0.58				
More accessible parking at health care center	INS165	1.20	1.18	0.56				
Transportation to do errands and go shopping	INS166	1.05	1.03	0.57				
Transportation to school or work	INS167	1.20	1.27	0.53				
Transportation for work or household activities	INS164	1.03	1.11	0.55				
RELATIONSHIPS ($\alpha=0.96$)					0.85	0.98	2.35	
Someone that I could really talk to	INS133	1.02	1.13	0.82				
Help with feeling alone	INS134	1.00	1.03	0.80				
Others to acknowledge the impact of cancer on my life	INS146	1.15	1.27	0.77				
Help dealing with changes in other people's attitudes/behavior toward me	INS136	1.11	1.11	0.77				
Help with difficulties with my family or spouse	INS135	0.99	0.93	0.79				

Subscales (α) and Items	Item ID	Rasch Item Calibrations and Fit Statistics					
		Infit	Outfit	PT-Measure Correlation	Person Reliability	Item Reliability	Separation Index
Help engaging in social activities because of physical health/emotional problems	INS132	1.05	1.03	0.77			
Help dealing with increased emotional problems at home	INS138	0.92	0.83	0.78			
Help dealing with increased tension or arguments at home	INS137	0.95	0.85	0.77			
Help talking about my health with my family and friends	INS149	0.95	1.02	0.75			
Help communicating with friends/relatives	INS140	0.86	0.82	0.76			
Help dealing with difficulty in interacting with friends/relatives	INS141	0.94	0.89	0.75			
To be more reassured by my relatives	INS147	0.91	0.93	0.75			
To feel more useful within my family	INS148	0.88	0.95	0.74			
Help interacting with partner/spouse	INS144	1.31	1.21	0.67			
Help taking part in community activities	INS139	1.00	0.97	0.71			
Help interacting with children	INS142	1.13	1.03	0.66			

Table 4

Test-retest reliability at 4, 5, 6, and 12

	4 wks (n=42)	5 wks (n=65)	6 wks (n=84)	12 wks (n=117)
Psycho-emotional	r = 0.80	r = 0.76	r = 0.75	r = 0.74
Health System Concerns	r = 0.52	r = 0.54	r = 0.60	r = 0.55
Cancer-related Information	r = 0.81	r = 0.81	r = 0.77	r = 0.76
General Health	r = 0.92	r = 0.79	r = 0.73	r = 0.75
Survivor Care/Support	r = 0.74	r = 0.76	r = 0.77	r = 0.68
Surveillance	r = 0.71	r = 0.60	r = 0.57	r = 0.53
Coping	r = 0.87	r = 0.88	r = 0.86	r = 0.81
Fiscal Concerns	r = 0.85	r = 0.86	r = 0.86	r = 0.80
Relationships	r = 0.91	r = 0.91	r = 0.88	r = 0.86

Table 5

Impact of Significantly Different Item Functioning on Subscale Measures

DIF Subscale*	Correlation: DIF Adjusted and Non-Adjusted Measures	RMSE	Intercept	Slope
Psycho-emotional				
INCOME	0.999	0.100	-0.0891	0.999
EDUCATION	0.999	0.159	-0.1242	0.999
Health System Concerns				
INCOME	0.999	0.072	0.0067	0.992
EDUCATION	0.999	0.089	-0.0098	0.996
Cancer-related Information				
INCOME	0.999	0.038	0.0010	0.993
EDUCATION	0.999	0.022	-0.0012	0.997
General Health				
INCOME	0.999	0.023	-0.0011	0.999
EDUCATION	0.998	0.129	-0.0226	1.000
Surveillance				
INCOME	0.999	0.063	0.0003	0.989
EDUCATION	0.999	0.164	-0.0198	0.995
Coping				
INCOME	0.999	0.091	-0.0079	0.994
EDUCATION	0.999	0.100	-0.0114	0.998
Fiscal Concerns				
INCOME	0.997	0.218	0.0118	0.974
EDUCATION	0.999	0.048	-0.0064	1.002

* Subscales showing significantly different item functioning in DIF analysis.

Table 6

Subscale Mean, SD, and Range by Demographic, Disease, and Treatment Covariates

Covariate	Psycho-Emotional		Health-System Concerns		Cancer-Related Information		General Health		Survivor Care/Support		Surveillance		Coping		Fiscal Concerns		Relationships	
	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range
Age (years)																		
25–39	24.77 (8.71) *		14.37 (4.97) *		19.04 (6.75) *		20.77 (6.66) *		26.86 (9.08) *		12.78 (4.76) *		16.41 (5.73) *		30.60 (9.66) *		20.34 (6.82) *	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
40 and older	27.21 (10.01)		15.93 (5.71)		21.37 (7.27)		23.39 (8.21)		29.70 (10.57)		14.45 (5.55)		18.29 (6.79)		32.31 (10.58)		21.27 (7.79)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Sex																		
Male	25.24 (9.67) *		14.48 (5.24) *		18.91 (7.16) *		21.03 (7.24) *		26.91 (9.58) *		12.84 (4.99) *		16.35 (5.99) *		30.72 (9.65)		20.01 (7.03) *	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Female	26.42 (9.26)		15.57 (5.46)		21.01 (6.94)		22.73 (7.70)		29.14 (10.06)		14.10 (5.32)		17.98 (6.49)		31.87 (10.43)		21.29 (7.46)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Minority Status																		
Caucasian	25.90 (9.37)		15.06 (5.31)		20.13 (7.08)		21.91 (7.51)		28.13 (9.85)		13.47 (5.10)		17.22 (6.23)		31.18 (9.89)		20.63 (7.22) *	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Non-Caucasian	26.42 (10.04)		15.71 (6.06)		20.55 (7.33)		23.12 (7.92)		29.16 (10.63)		14.60 (6.11)		18.33 (7.22)		33.54 (12.02)		22.08 (7.97)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Residence																		
Urban	26.02 (9.51)		15.13 (5.44)		20.08 (7.09)		21.87 (7.39)		28.21 (9.82)		13.58 (5.19)		17.30 (6.31)		31.35 (10.04)		20.65 (7.13)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Rural	25.59 (9.06)		15.13 (5.18)		20.66 (7.19)		23.05 (8.42)		28.32 (10.49)		13.66 (5.44)		17.50 (6.52)		31.78 (10.70)		21.56 (8.24)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Education																		
Less than college	26.57 (9.96)		15.60 (5.76) *		20.39 (7.43)		23.33 (8.70) *		29.43 (11.06) *		13.98 (5.70)		17.94 (6.82) *		34.08 (11.89) *		21.82 (8.28) *	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
College graduate	25.60 (9.12)		14.86 (5.15)		20.06 (6.91)		21.25 (6.67)		27.46 (9.10)		13.33 (4.89)		16.93 (5.98)		29.84 (8.60)		20.11 (6.50)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–69		16–48	
Income																		

Covariate	Psycho- Emotional		Health- System Concerns		Cancer- Related Information		General Health		Survivor Care/Support		Surveillance		Coping		Fiscal Concerns		Relationships	
	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range
\$59,999/year	27.76 (10.17) [*]		15.79 (5.66) [*]		20.55 (7.29)		23.33 (8.27) [*]		29.72 (10.86) [*]		14.02 (5.58) [*]		18.22 (6.67) [*]		34.03 (11.70) [*]		22.05 (8.25) [*]	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
	24.75 (8.67)		14.55 (5.08)		19.94 (6.91)		21.08 (6.91)		26.94(8.86)		13.28 (4.91)		16.63 (5.90)		29.30 (8.20)		19.86 (6.44)	
\$60,000/year	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Relationship Status																		
Married/living partner with	25.11 (8.85) [*]		14.80 (5.22) [*]		20.01 (7.12)		21.52 (7.38) [*]		27.63 (9.68) [*]		13.42 (5.02)		16.67 (5.87) [*]		30.07 (8.91) [*]		19.98 (6.77) [*]	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
	27.43 (10.22)		15.70 (5.66)		20.43 (7.04)		22.94 (7.74)		29.29 (10.24)		13.90 (5.58)		18.52 (6.96)		33.94 (11.72)		22.24 (8.03)	
Single/divorced/widowed/separated	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Diagnosis [†]																		
^a Leukemia	25.35 (9.18) ^h		14.65 (5.09) ^e		19.96 (7.11) ^e		21.29 (6.84) ^{ch}		26.87 (9.20) ^{ch}		13.47 (5.24) ^e		17.03 (6.26)		31.02 (9.74) ^h		20.69 (7.10)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
	26.53 (10.20)		15.64 (5.84)		18.79 (7.47) ^e		22.44 (8.06) ^{ch}		28.77 (11.03)		13.26 (5.66)		17.75 (7.03) ^e		33.34 (12.10) ^e		21.74 (8.15) ^e	
^b CNS	17–51		10–30		11–33		16–47		20–60		9–27		12–36		24–69		16–48	
^c HD	28.23 (10.06) ^e		16.93 (5.64) ^{aeefg}		22.70 (6.94) ^{abdefg}		25.82 (8.70) ^{abdefg}		31.76 (10.56) ^{aeef}		15.16 (5.38) ^{aeef}		19.00 (6.66) ^e		33.20 (10.47) ^e		21.51 (7.78) ^e	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
	25.67 (8.66)		15.39 (5.41)		20.58 (7.52)		21.52 (7.51) ^{ch}		27.97 (9.89)		13.10 (4.64)		17.34 (6.16)		29.67 (8.16) ^h		19.99 (7.00)	
^d NHL	17–51		10–30		11–33		16–47		20–60		9–27		12–36		24–62		16–48	
^e Kidney (Wilms)	22.82 (7.27) ^{ch}		13.61 (4.52) ^{ch}		18.78 (6.41) ^e		19.24 (5.36) ^{hch}		26.62 (9.38) ^{ch}		12.39 (4.53) ^{ch}		15.02 (4.74) ^{beh}		28.30 (7.24) ^{beh}		18.38 (5.32) ^{beh}	
	17–47		10–29		11–33		16–36		20–58		9–27		12–35		24–72		16–46	
	24.63 (8.14)		14.35 (5.62) ^e		19.42 (6.79) ^e		19.83 (5.59) ^{ch}		25.88 (7.96) ^{ch}		12.75 (4.73) ^e		16.38 (5.01)		30.14 (10.58) ^h		20.00 (6.26)	
^f Neuroblastoma	17–50		10–29		11–33		16–35		20–48		9–27		12–33		24–68		16–39	
^g Soft tissue sarcoma	26.19 (9.45)		14.65 (5.00) ^e		19.71 (7.00) ^e		21.13 (6.64) ^{ch}		28.66 (10.01)		13.36 (4.81)		17.25 (6.38)		30.34 (9.57) ^h		20.93 (7.23)	
	17–51		10–30		11–33		16–42		20–56		9–27		12–35		24–72		16–46	
	29.29 (10.99) ^{ae}		16.26 (5.88) ^e		21.84 (6.30)		26.12 (9.28) ^{abdefg}		31.54 (10.21) ^{aeef}		15.26 (5.72) ^e		19.36 (6.89) ^e		35.98 (11.43) ^{abdefg}		23.24 (8.70) ^e	
^h Bone cancer	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Treatment [†]																		
^a Chemotherapy only	24.71 (9.22) ^d		14.19 (5.08) ^{bd}		19.57 (6.73) ^e		20.82 (7.01) ^{bd}		26.22 (8.56) ^{bd}		12.88 (4.75) ^{bd}		16.45 (5.89) ^d		30.26 (9.26)		19.86 (6.67)	

Covariate	Psycho- Emotional		Health- System Concerns		Cancer- Related Information		General Health		Survivor Care/Support		Surveillance		Coping		Fiscal Concerns		Relationships	
	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range	M (SD)	Range
b Radiation only	17–51		10–30		11–33		16–48		20–54		9–27		12–36		24–72		16–48	
	26.94 (10.38)		16.45 (5.82) ^{ac}		21.04 (7.38) ^c		22.89 (7.95) ^{ac}		30.13 (10.64) ^{ac}		14.34 (5.84) ^{ac}		18.08 (6.70) ^c		32.58 (11.72)		21.29 (8.21)	
c Surgery only	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–69		16–48	
	23.84 (8.11) ^d		13.66 (4.95) ^{bd}		16.73 (5.98) ^{bbd}		19.59 (6.08) ^{bd}		26.00 (8.03) ^{bd}		12.27 (4.50) ^{bd}		15.32 (4.96) ^{bd}		29.33 (9.40)		19.82 (6.70)	
d Chemo + radiation	17–49		10–30		11–33		16–42		20–51		9–27		12–30		24–72		16–47	
	26.67 (9.53) ^{ac}		15.61 (5.46) ^{ac}		20.97 (7.18) ^c		22.90 (7.83) ^{ac}		29.17 (10.47) ^{ac}		14.07 (5.36) ^{ac}		18.07 (6.66) ^{ac}		31.90 (10.17)		21.34 (7.58)	
Years since diagnosis	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
	25.95 (9.37)		15.05 (5.41)		20.00 (6.88)		21.65 (7.18)		28.25 (9.76)		13.37 (4.96)		17.29 (6.15)		31.37 (10.10)		20.63 (6.99)	
<28.16 years	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
	25.95 (9.51)		15.20 (5.39)		20.33 (7.31)		22.41 (7.90)		28.21 (10.09)		13.81 (5.47)		17.37 (6.52)		31.46 (10.19)		20.95 (7.62)	
28.16 years	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
Age at diagnosis †																		
a 4 years	24.21 (8.54) ^{cd}		14.02 (4.85) ^{bcd}		18.86 (6.69) ^{cd}		20.36 (6.52) ^{cd}		26.64 (9.23) ^{cd}		12.57 (4.62) ^{cd}		16.05 (5.53) ^{cd}		30.77 (10.14)		19.85 (6.54) ^c	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
b 5–9 years	26.19 (9.75)		15.21 (5.60) ^a		19.86 (7.50) ^d		21.70 (7.35) ^d		27.40 (10.17) ^d		13.60 (5.67) ^d		17.37 (6.74) ^d		30.39 (9.37)		21.02 (7.41)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–68		16–48	
c 10–14 years	26.70 (9.59) ^a		16.00 (5.67) ^a		21.12 (7.20) ^a		23.40 (8.12) ^a		29.44 (9.94) ^a		14.08 (5.36) ^a		18.07 (6.69) ^a		32.34 (10.85)		21.64 (8.00) ^a	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	
d 15–20 years	28.42 (10.00) ^a		16.33 (5.49) ^a		22.14 (6.77) ^{ab}		24.46 (8.30) ^{ab}		31.00 (10.25) ^{ab}		15.11 (5.30) ^{ab}		19.08 (6.50) ^{ab}		32.88 (10.01)		21.51 (7.76)	
	17–51		10–30		11–33		16–48		20–60		9–27		12–36		24–72		16–48	

* Independent samples t test *P* < 0.05.

† Letter superscripts are assigned to each variable category. Letter superscripts after mean/SD indicate that the mean differs significantly (*P* < 0.05 after Bonferroni correction) from the mean of the category indicated by the letter.