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The Unmet Emotional, Care/Support, and Informational Needs of Adult Survivors of Pediatric Malignancies

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Abstract

Purpose—Describe the prevalence and predisposing factors for potentially modifiable unmet emotional, care/support, and information needs among adult survivors of childhood malignancies.

Methods—A randomly selected/stratified sample of participants in the Childhood Cancer Survivor Study (CCSS) responded to the *CCSS-Needs Assessment Questionnaire (CCSS-NAQ)* (n=1189; mean [SD] current age, 39.7 [7.7], range=26–61 years; 60.9% women; mean [SD] years since diagnosis, 31.6 [4.7]). Survivors self-reported demographic information, health concerns, and needs; diagnosis/treatment data were obtained from medical records. Adjusted proportional risk (PR) ratios were used to evaluate 77 separate needs.

Results—Fifty-four percent of survivors reported unmet psycho-emotional, 41%, coping, and 35%, care/support needs; 51%, 35%, and 33%, respectively, reported unmet information needs related to cancer/treatment, the health care system, and surveillance. Female sex and annual income <\$60K were associated with multiple needs; fewer needs were linked to diagnosis/years since/ or age at diagnosis. Having moderate/extreme cancer-related anxiety/fear was associated with all needs, including a >6-fold increased prevalence for help dealing with "worry" (PR=6.06;

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Ethical Approval: All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The overall study was approved by the St. Jude Children's Research Hospital Institutional Review Board and at each of the 27 participating institutions in the Childhood Cancer Survivor Study.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

95% CI, 3.79 – 9.69), anxiety (PR=6.10; 95% CI, 3.82–9.72), a >5-fold increased prevalence for "needing to move on with life" (PR=5.56; 95% CI, 3.34–9.25), and dealing with "uncertainty about the future" (PR=5.50; 95% CI, 3.44–8.77). Radiation exposure and perceived health status were related to 42 and 29 needs, respectively.

Conclusions—Demographic factors, disease/treatment characteristics, and intrapersonal factors can be used to profile survivors' unmet emotional, care/support, and information needs.

Implications for Survivors—These data can be used to enhance provider-survivor communication, identify at-risk subsamples, and appraise core intervention content.

Keywords

cancer; oncology; survivors; childhood cancer; health-related needs

BACKGROUND

Adult survivors of pediatric malignancies are likely to manifest different needs at different time points given the heterogeneity of childhood cancers, treatment exposures, survivor behaviors, and informed access to health care [1]. For example, more than 60% of 879 adults (aged 18–39 years) who had experienced childhood cancer expressed a need for age-appropriate cancer-related information, and more than 50% of these respondents indicated that their needs for information and services were unmet [2, 3]. A cohort of 526 adult survivors of childhood central nervous system (CNS) tumors (age range, ≥18 to >36 years; mean age, 26 years) identified psychosocial services (40%), education about their illness (35%), care coordination (22%), and medical care (15%) as their most pressing needs [4]. However, studies generally have not reported the comprehensive needs of childhood cancer survivors older than 40 years —the population most likely to experience multiple health needs as a result of their escalating chronic illnesses or complications of late effects [5]— or addressed needs in sufficient detail to specifically inform tailored interventions.

While almost all pediatric cancer programs offer survivorship services, a variety of factors contribute to survivors' lack of uniform access to such programs [6]. Among pediatric aged survivors, preferences by treating oncologists to supervise long-term care or survivors' and their families' reluctance to transition care may result in follow-up evaluations largely focused on primary cancer surveillance [7]. In older survivors, age restrictions for delivery of care in pediatric institutions necessitate transition of care; in the best of these situations, transition is facilitated by the nearby availability of a long-term follow-up program serving adults with cancer [6]. Specialized survivorship programs are becoming increasingly available in cancer centers and community settings, but geographic and financial factors also limit survivors' access [8, 9]. Ultimately, the vast majority of childhood cancer survivors will have primary care transitioned to community providers who are generally unfamiliar with the health risks or health needs predisposed by cancer treatment, some of which manifest many years following exposure [10, 11]. To comprehensively address the health care needs of childhood cancer survivors, risk-based care that integrates the cancer experience within the context of primary care is recommended for all survivors [12]. Risk-based care involves a personalized plan of surveillance for primary cancer, screening for health related effects of cancer and its treatment, and health counseling regarding methods to mitigate cancer-related toxicity. A survivorship care plan that delineates the cancer history, specific treatment modalities, risk-based screening and surveillance plans and the roles of clinicians participating in long-term follow-up care has been promoted as an important tool to facilitate communication and coordination of survivorship care, particularly among those who do not have access to specialty programs supervised by clinicians familiar with health issues experienced by childhood cancer survivors [13]. Adding an assessment of health-related needs to this care plan would make a significant contribution to long-term care of childhood cancer survivors. Using a comprehensive, valid, and reliable multi-dimensional health-related needs measure [14], we provide the first report on the emotional, care/support, and information needs of a large sample of adult survivors of childhood cancer. We aimed to assess the associations between unmet needs and demographic, disease, treatment, health status, and intrapersonal characteristics. Based on extremely limited prior information, we hypothesized that these factors would be variably associated with unmet needs.

METHODS

Data source

The CCSS is a 27-institution cohort study (IRB approval obtained at each participating institution) that follows more than 10,000 geographically and socio-economically diverse long-term survivors (i.e., those who completed therapy for a pediatric malignancy at least 5 years previously) [15,16]. The study, which involves retrospective plus prospective ascertainment of late effects, was initiated in 1994 to track survivors of pediatric cancers diagnosed and treated between 1970 and 1986. Survivors completed a baseline questionnaire at study entry and responded 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 previously described [15,16].

Sample

CCSS participants who were treated at St. Jude Children's Research Hospital were excluded to assure a more homogeneous sample in terms of the cancer treatment experience and survivors' need perceptions. St. Jude provides comprehensive medical and psychosocial services to all patients regardless of their ability to pay and continues patient care until the survivors reach 18 years of age or 10 years from diagnosis and periodic (every 5 years) cancer-related consultation in adult survivors participating in the St. Jude Lifetime Cohort Study[17]. Survivors younger than 25 years as of December 31, 2009, were also excluded, allowing us to focus on those unlikely to be covered by parental health insurance or by federal/state insurance for children and adolescents. Requiring a minimal sample of 1000 survivors to complete our psychometric analysis of the CCSS-NAQ, we selected a stratified (age, sex, diagnosis) random sample of 1430 survivors drawn from the total eligible sample (N=4454) on the basis of previous CCSS cohort participation rates. We used inverse weighting probabilities in our analysis for African American, Hispanic, and rural-residing (i.e., those for whom a Rural Urban Commuting Area Code was tied to their small town or those who resided in smaller, rural census tracts) survivors to maximize sample diversity. Only 36 survivors in the initial mailing returned a questionnaire. Using phone and electronic tracing methods in our survey research laboratory, forwarding addresses, and sending out an additional 1660 questionnaires (as many as 4 questionnaires to one individual with 4 re-location addresses) we were able to solicit 1178 useable questionnaires for our psychometric analysis of the CCSS-NAQ; an additional 11 survivors provided useable questionnaires after the psychometric analysis was completed for a participation rate of 83% and a questionnaire return rate of 39% (Supplement Figure 1).

Data collection and study measures

The questionnaire booklets were mailed to participating survivors with a pre-addressed, stamped return envelope and included the needs assessment instrument and demographic and health care access questions. The demographic variables included sex, race, marital status, two indicators of economic status (highest household education/household income), and employment status. Insurance status and health care access were assessed by using index items from the National Health Interview Survey [18] and the CCSS cohort survey [15, 16]. Data related to childhood cancer (diagnosis, date of diagnosis, interval since diagnosis, treatment exposures) were obtained from the medical records of the CCSS database. *Common Terminology Criteria for Adverse Events (CTCAE)* [19], a calculated variable developed by the National Cancer Institute, scores both acute and chronic conditions in patients with cancer and in cancer survivors of all ages; conditions are graded as none (grade 0), mild (grade 1), moderate (grade 2), severe (grade 3), life-threatening or disabling (grade 4), or fatal (grade 5). For participants who had more than one condition, the grade of the most advanced condition was used in the analysis.

Health-related concerns and cancer-related fear/anxiety items were derived from the most recent CCSS cohort follow-up survey completed during the same time interval as the *CCSS-NAQ*.

The five single items are listed below.

- “Do you currently have anxieties/fears as a result of your cancer or treatment?”

  (Response options ranged from (1) no anxiety/fears to (5) very many, extreme anxiety/fears)

- “Please rate how concerned you are about the following:”
  - “your ability to have children”,
  - “developing cancer in the future”,
  - “your ability to get life insurance”, and
  - “your ability to get health insurance”.

  (Response options for these four items ranged from (1) not at all concerned to (5) very concerned.)

Need outcomes

The CCSS-NAQ was developed to comprehensively assess the health-related needs of adult survivors of childhood cancer. The instrument [14] includes 135 items composing 9 unidimensional subscales (*Psycho-emotional*, *Health System Concerns*, *Cancer-related Health Information*, *General Health*, *Survivor Care and Support*, *Surveillance-related Information*, *Coping, Fiscal Concerns*, and *Relationships*). Confirmatory factor analysis (n=1178; RMSEA = 0.02; 90% CI = 0.019 – 0.020; CFI = 0.96; TLI = 0.96) and person-item fit variable maps were used to assess construct validity. Across subscales, Cronbach's alpha coefficient was 0.94–0.97 and test-retest stability was 0.54–0.84. 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. For this analysis, survivors who had no need or met needs were compared to those reporting low-, moderate-, or high-level unmet needs. This report is limited to findings from the 77 individual items composing the *Psycho-emotional, Care/Support, Coping, Health System Concerns, Cancer-related*, and *Surveillance-related Information* subscales. Information from these specific subscales could be immediately incorporated into clinical practice: the *General Health, Relationships, and Fiscal Concerns* subscales would likely require supplemental information and additional resources beyond the oncologist or primary care provider.

Analysis

Although each item in a Rasch-derived subscale contributes to the overall construct of that subscale, the item measures discrete content. Individual items can serve as stand-alone items (e.g., "need help with always feeling tired") or contribute to the overall subscale (e.g., "general health"). Overall and stratum-specific prevalence of 77 individual need items [(1) no need, need met; (2) low-, moderate-, high-level need] were assessed (Table 1).

Log-binomial regression was used to estimate prevalence ratios (PRs) [20] and corresponding 95% confidence intervals (CIs) for the associations between exposures of interest (demographic, disease/treatment factors, and intrapersonal factors) and the 77 need items. *A priori* dependency assumptions were encoded in a directed acyclic graph (Supplement Figure2) to assess potential confounding pathways that required adjustment [21], and applied the back-door criterion to the fully encoded directed acyclic graph to identify a minimal sufficient set of covariates for adjustment (Supplement Table 1) to reduce confounding bias for each exposure-outcome association [21, 22]. The minimal sufficient set of covariates relevant to each exposure-outcome association of interest was subsequently adjusted in the corresponding multivariable log-binomial model. For example, when estimating PRs of the association between radiation therapy and care/support needs, the minimal sufficient set was current age, age at diagnosis, and diagnosis group. Only associations with P-values less than 0.05 are reported in Tables 2 – 4.

RESULTS

The sample (n=1189) was predominantly female, non-Hispanic white, married, college educated, and employed full-time with a median annual income of $60,000–$99,999 (Table 1). Leukemia was the most frequent diagnosis (33.7%) and most of the responders' diseases were diagnosed between the ages of 0–4 years. Non-respondents were slightly more racially diverse; 4.6% were African American and 7.6% were Hispanic ($P = 0.002$), and more than half were male (51.2%; $P < 0.001$). Although most responders and non-responders resided in urban areas, survivors from rural areas were well represented (15.3% of responders and 10.6% of non-responders [$P < 0.001$]). Non-responders did not differ from the study sample in age, age at diagnosis, type of diagnosis, or years since diagnosis.

Demographic links to unmet needs

Twenty-five percent of the sample report no needs or met needs; 51% of the sample endorsed ≤ 9 needs; only 1% of survivors endorsed ≥70 unmet needs; 4% of the sample endorsed ≥60 needs; 7% endorsed ≥50 needs; 12%, ≥40 needs. More than half of the survivors who reported needs endorsed having unmet psycho-emotional (54%) and cancer-related information (51%) needs; 35% of the sample reported care/support and health care system concerns; 41% reported coping needs, and 33% of the sample reported surveillance-related needs (Table 1). Being female was associated with having ≥ 50% unmet care/support (Supplement Table 2A) and coping needs (Supplement Table 2B); women endorsed more than 75% of the unmet health-system concerns and cancer-related information needs (Supplement Table 4A–B). Having less than a college education was associated with 17 of 20 care/support needs (Supplement Table 2A), 3 cancer-related information needs (Supplement Table 4A), 4 health-system concerns (Supplement Table 4B), and 5 surveillance-related needs (Supplement Table 4C), and 3 coping needs (Supplement Table 2B). Having a total household income <$60K was associated with all psycho-emotional (Supplement Table 3), coping (Supplement Table 2B), care/support (Supplement Table 2A), and health system concerns (Supplement Table 4B) and 5/8 surveillance-related needs (Supplement Table 4C), but only 2/11 cancer-related information needs (Supplement Table 4A). Survivors who were single, separated, or divorced were more likely than those in a relationship to report having psycho-emotional (9/16) (Supplement Table 3) and 11/12 coping needs (Supplement Table 2B). Race, residence (rural vs. urban), employment, availability of primary care, number of MD visits, number of cancer-related visits, surgical intervention, concern about getting life insurance, time since last medical check-up, and next scheduled check-up were not associated with any of the 77 needs.

Disease and treatment links to unmet needs

Compared to having a diagnosis of solid tumors (including bone cancer), having a diagnosis of Hodgkin lymphoma or leukemia/non-Hodgkin lymphoma resulted in having more unmet needs, with larger prevalence ratios. For example, Hodgkin lymphoma was associated with 14 unmet needs; leukemia/non-Hodgkin lymphoma diagnoses were linked to 11 unmet needs across all subscales (Tables 2–4). Similarly, a diagnosis of CNS tumor increased the prevalence ratios for unmet needs across all subscales except coping. Of note, a CNS tumor diagnosis was protective against 4 unmet cancer-related information needs (Table 4A) and 1 surveillance-related need (“need information about what screening tests I should have based on treatment history”) (Table 4C).

Receiving a pediatric malignancy diagnosis at 5–14 years of age was associated with 17 needs (particularly care/support and coping [Supplement Table 2 A–B]); a diagnosis at 15–20 years old resulted in a higher prevalence of 15 unmet needs across all subscales except care-support and surveillance. Survivors diagnosed 28–31 years ago had an increased prevalence for needing help with “getting MD to be confident in their choices” (PR=2.11, 95% CI, 1.03–4.33), and "getting MD to be more accepting" (PR=2.40, 95% CI, 1.11–5.19 (Supplement Table 2A). Compared to those with fewer years since diagnosis (i.e., 24–31 years), survivors diagnosed 32–42 years ago were protected against 3 unmet needs: "knowing diseases that can result from cancer therapy (PR=0.63, 95% CI, 0.41–0.96)", "what I can do to reduce my chances of late effects (PR=0.65, 95% CI, 0.43–0.99)"and "what screening tests I need based on treatment history"(PR=0.59, 95% CI, 0.37–0.93) (Supplement Tables 4A&C).

Chemotherapy had no association with psycho-emotional or coping needs, but was linked to 10/20 care/support, 6/11 cancer-related information, and 3 surveillance-related needs (Tables 2A, 4A&C). Radiation exposure was associated with 13 of 16 psycho-emotional needs (Table 3) and all care/support (Table 2A), 9/12 coping (Table 2B), 9/11 cancer-related information (Table 4A), 7/10 health system (Table 4B), and 1/8 surveillance-related needs (Tables 4C).

Health Status, Chronic Conditions, and Long-term Care

Compared to a health perception of "excellent/very good", a survivor's perceived health status of "good/fair/poor" was associated with 13 psycho-emotional needs, with the highest PR for "need help feeling in control of my situation"; 2 of 20 care/support needs, with the highest PR for "need to have more trust in my physician"; 8 of 12 coping needs, with the highest PR for "need help moving on with my life", and 5 of 11 cancer-related information needs, with the highest PR for "need information about how cancer affected my body". Health status was associated with only one health care system concern ("need information about support groups in my area") and no surveillance-related needs. Survivors with severe or life-threatening chronic problems (Grades 3–4) reported having 5 of 16 psycho-emotional and 6 of 20 care/support needs, with the largest PR for "need help to share feelings with MD." Receiving follow-up care at a long-term follow-up (LTFU) oncology clinic rather than elsewhere increased survivors' risk for reporting 6 psycho-emotional needs, one care/support needs ("need help to share feelings with MD"), and 1 health care system concern ("need to be treated like a person, not just another case") (Tables 2A–4A).

Concerns and Worries

"Concern about the ability to have children" was associated with 1surveillance, 11 of 20 care/support, 6 of 10 health-care system, and 8 cancer-related information needs. Survivors' "concern about the ability to obtain health insurance" was associated with 68/77 unmet needs across all subscales. "Concern about cancer returning" did not affect the psycho-emotional or care/support items but was associated with 3/12 unmet coping needs (Table 2B), 1/10 health care system concerns (Table 4B), 6/11 cancer-related information needs (Table 4A), and 5/8 surveillance-related needs (Table 4C). "Moderate to extreme anxiety" about having had cancer/treatment was significantly associated with all 77 needs (Tables 2–4); prevalence risks ranged from 1.86 (95% CI, 1.12–3.08) for "need help for feelings of boredom/uselessness" to 6.10 (95% CI, 3.82 – 9.72) for "need help dealing with anxiety".

DISCUSSION

To our knowledge, this is the first effort to document a broad array of highly specific health-related needs in a large population of adult survivors of childhood cancer. We examined individual needs rather than categories of needs and observed that these needs are influenced differentially by demographic, disease, treatment, and intrapersonal factors. Eight of the 21 factors examined were consistent major influences on unmet needs: female sex; household income <$60K; diagnosis between the ages of 5 and 14 years; perceived health status of good, fair, or poor; moderate/extreme concerns about the ability to obtain health insurance; radiation exposure; fear about cancer recurrence; and moderate or extreme cancer/treatment-related anxiety or fear.

Males reported having fewer unmet needs than did women, which is consistent with studies of men in the general population; although men realize that they may have health-related needs, they may readily dismiss them and take no action to address them [23]. Although lower levels of income and education were associated with care/support needs, coping and psycho-emotional needs were linked to income but not to education. A lower income was uniquely associated with needing information about after-cancer care, support groups, access to professional counseling, needing doctors to talk to each other, and needing information about who to call for help. These needs, for the most part, are linked to the availability/accessibility of health care resources for resolution, resources that may not be within reach of those with lower incomes or inadequate health insurance [24].

Compared to those with other diagnoses, survivors of CNS tumors were more concerned with provider sensitivity—needing questions to be addressed fully and their opinions to be valued—and were more likely to need help maintaining control/positive outlook. CNS tumor survivors commonly experience cognitive impairment [25] including compromises in memory, fatigue, and executive function [26]. These factors contribute to higher stress levels and inadequate coping abilities [27]. These survivors' higher reporting of care/support and psycho-emotional needs likely reflects these difficulties.

Alternatively, a diagnosis of CNS tumor was protective against 6 unmet needs. In the US, because of the substantial risks of cancer- and treatment related adverse health effects (i.e., development of new endocrine, neurological, neurosensory, and neurocognitive impairment [28]), survivors of CNS tumors often receive high-quality long-term follow-up care in specialized cancer centers. Thus it is more likely that during treatment and in follow-up, their progress is carefully monitored, their multiple needs anticipated, and interventions to modify risks are implemented. Therefore, these survivors, in contrast to others who may be less frequently monitored by specialists in survivorship care (e.g., those with Hodgkin lymphoma, leukemia, or non-Hodgkin lymphoma), are in an optimal position to have many of their health care system concerns, cancer-related information needs, and surveillance needs assessed and met.

Survivors whose disease was diagnosed between the ages of 5 to 14 years and, to a lesser extent, adolescents whose disease was diagnosed between 15 to 20 years of age reported a higher prevalence of unmet needs. Experiencing numerous and prolonged hospitalizations at critical developmental periods (e.g., school-age, adolescence) is a significant risk factor for developmental problems and associated health-related needs [29]. School-aged children are normally developing friendships and seeking approval from their peer group; they are learning impulse control, what constitutes appropriate behavior, and physical and artistic mastery. These behavioral skills ultimately inform a new sense of personal competence and are the foundation for children’s self-evaluation in comparison to their peers [30]. Adolescents, in particular, can face a significant loss of independence and disruption of their social relationships at a time when they should be developing social and relationship skills critical to successful functioning in adulthood [31]. That children diagnosed at these critical times, in contrast to between 0 and 4 years, would endorse more needs is not surprising.

Compared to survivors diagnosed more than 31 years ago, survivors diagnosed more recently endorsed needs related to their expectations of physician communication and the need to make sense of their illness. A patient’s age is associated with the preferred style of patient-provider interaction: older patients are more accepting of an authoritative physician interaction style, whereas younger patients expect a more consultative style with more shared decision making [32, 33, 34].

Survivors diagnosed 32–42 years ago were protected against the prevalence of several needs. CCSS data [35] demonstrate that 30 years after diagnosis, almost three-fourths of the study sample had a chronic health condition; more than 40% had a condition that was severe, life threatening, disabling or fatal; and 39% had multiple conditions (excluding mental health problems). These survivors may be receiving regular care for chronic illness and, as a result, are likely receiving information that would reduce their needs for information and communication within the health care setting. Follow-up for these chronic conditions may put some of these survivors in an optimal position to receive the information they need.

Surgical intervention was not associated with any unmet needs. Improved surgical techniques (organ and tissue sparing rather than radical surgery) have significantly reduced the health-related needs of these survivors [36]. Chemotherapy was primarily associated with provider interaction/communication needs. Endorsement of these needs may partially reflect an individual’s specific chemotherapy exposure and consequent outcomes—lower IQ; problems with memory, attention, and processing; and lower self-esteem [24]—problems that would logically necessitate repeated reassurance, greater acceptance, and a need for trust in the care provider. Because radiation is linked to so many risks for subsequent health conditions [37], those treated with radiation may report substantially more needs than those who did not receive radiation therapy.

Receiving care at an LTFU oncology clinic was associated with psycho-emotional needs, care/support needs, and health-care system concerns: these needs emphasized reassuring provider communication, reducing fear/anxiety, and maintaining a positive outlook. Survivors of pediatric malignancies are more likely to receive risk-based information at LTFU clinics because of these clinics’ familiarity with LTFU guidelines [38]; similarly, risk-based information provided to survivors at LTFU clinics will likely exceed (in quantity and specificity) that provided by primary care physicians [39]. This information may generate uncertainty, anxiety, and fears about future disability. Moreover, in survivor-specific care settings, survival and monitoring for late effects are currently the critical outcomes and the principal concerns, with the long-term care focus being on physical manifestations of late effects [40, 41]. Our results suggest that it is easier to address/provide interventions for medical issues and potentially more challenging to address/remediate psychosocial issues.

Perceived health status (good/fair/poor) and a chronic disease grade of 3–4 (severe/life threatening) were associated with multiple needs. Survivors of childhood cancer have much higher than average rates of chronic illness beginning in their early or middle adult years. The results of recent studies show that the cumulative incidence of a severe, disabling, life-threatening, or fatal health condition among these survivors is approximately 4-fold greater than that of siblings [42], underscoring the importance of life-long follow-up of childhood cancer survivors that integrates screening, health counseling, and intervention pertinent to the risks imposed by their cancer and its treatment.

Moderate to extreme fear/anxiety related to cancer, its treatment, or both was associated with all needs modeled. Anxiety is more common among cancer survivors than among the general population [43]. Although most childhood cancer survivors have normal psychological functioning [44, 45, 46], distressed psychological states may give rise to multiple needs. Adult patients with cancer who do not have psychological clinical syndromes still experience worries, fears, anxiety, and other forms of psychological stress; they report fear about the future, inability to make plans, uncertainty, and a heightened sense of vulnerability. Mood disturbance, fear of cancer recurrence, and concerns about body image are common in adults with cancer and in survivors of adult cancer. Chronic illness post-cancer in adults can cause feelings of loss of control, anger, sadness, guilt, and confusion [47, 48]. Thus, it is not surprising that dealing with these same issues would surface as unmet needs in adult survivors of pediatric malignancies.

Concern about the ability to obtain health insurance was linked to 48 of 77 unmet needs. Fewer than half of the adult survivors followed in the CCSS received a cancer-related visit in the preceding 2 years, and patients without health insurance had the highest prevalence of lack of appropriate follow-up [49]. Difficulty acquiring health insurance has been well documented as a common problem for adult survivors of pediatric malignancies [41, 50]. At the time of this needs assessment, the Affordable Care Act (ACA) had not been signed into law, and childhood cancer survivors were still facing the possibility of 1) being denied coverage due to pre-existing conditions, 2) charged more for coverage because of health status, 3) annual/lifetime coverage limits that could result in sudden termination of care, or 4) having to choose between life-saving screening and their life savings because they lacked access to affordable coverage. Provisions of the ACA are expected to help pediatric cancer survivors to gain or retain insurance coverage [41], and health insurance concerns in the future will not likely be of the magnitude demonstrated in this study.

Our results should be interpreted in the context of several limitations. Despite our efforts to oversample under-represented populations, minority participation was suboptimal, and thus our analyses may be underpowered to detect racial differences in unmet needs. Despite a very poor questionnaire return rate (39%), we had the resources to track these survivors and to send multiple questionnaires to the same individual when new addresses were located.

Most non-responders were men, and more responders than expected were well educated. Our estimates for the reported exposure-outcome associations may, therefore, be sensitive to bias because participation in this study was conditional on certain factors associated with our outcomes of interest. The magnitude and direction of bias is difficult to speculate without additional information on non-participants and would likely vary between exposure-outcome associations. Another consideration is that some of our observed effect estimates (e.g. for self-reported health status and perceived unmet needs) may be sensitive to differential dependent misclassification [51]. Although the direction of bias is unpredictable [52, 53], bias away from the null could be an alternate explanation for some observed associations. Furthermore, exposure and outcome measurements were cross-sectional in our study, so interpretations of associations may be subject to temporal ambiguity. For example, the temporal order of exposure and outcome is clear for demographic and disease/treatment variables in relation to unmet needs, but greater uncertainty arises about the temporal order between unmet needs and health-related concerns and worries. Longitudinal studies may be better suited for delineating temporal order. Finally, despite the large size and heterogeneity of the CCSS cohort, our results may not be generalizable to all childhood cancer survivors.

CONCLUSIONS

There is a high prevalence of unmet emotional, care/support, and information needs among adult survivors of pediatric malignancies. Survivor sub-samples identified as being at risk were those with incomes ≤$60K annually; women, who had increased need reporting; and men, who likely underreport their health-related needs. Additional survivors at risk are those who with a history of Hodgkin lymphoma, leukemia, or non-Hodgkin lymphoma who may not have specialist follow-up or are not seen as frequently as CNS tumor survivors; those whose disease was diagnosed between 5–14 years of age; those exposed to radiation; those concerned about cancer returning or the ability to have children; and those who are moderately or extremely anxious/fearful about their cancer/treatment. Two factors seemed to be protective against selected unmet needs: a diagnosis of CNS tumor and a longer time since diagnosis (32–42 years); both factors are likely related to the intensified care provided to CNS tumor survivors in the US and the increased frequency of care provided to long-term survivors, who may have multiple chronic illnesses.

Implications for Adult Childhood Cancer Survivors

This study points to several factors that can immediately be considered for practice implementation to tailor long-term care of adult pediatric cancer survivors. Evidence suggests that patients want providers to ask about their health-related needs, but assessment is often unsystematic and providers frequently focus only on specific presenting problems [54]. Professionals' varying ability to elicit relevant information, and patients' inability or reluctance to volunteer their needs and concerns [55] all contribute to poor documentation of needs. Clinician awareness of the risk groups identified and the nature of the many survivor needs that may go "unspoken" should be included as potential focal points during the clinical encounter.

Several communication needs were endorsed by this sample – to be treated more like a person than a disease, having complaints heard and addressed, better coordination and consolidation of medical care. Clinicians should be proactive in asking all survivors about their level of anxiety/worry about cancer-related issues and in asking Hodgkin lymphoma survivors to what extent multiple psycho-emotional needs are concerning and be prepared to refer them to resources for help. Open, highly supportive communication is essential for CNS tumor survivors; assuring that they are provided with resources to facilitate coping strategies would be a particularly important intervention target. Clinician awareness that survivors have certain expectations about interaction/communication (e.g., opportunities for input/choice, greater provider sensitivity) is essential. A communication style that encourages survivor dialogue and welcomes input can be highly useful in beginning to address many of the needs reported here.

The sample endorsed several unmet needs related to the content of information that should be communicated: more discussion of late effects and how they can be modified, more information about symptoms and medications, and greater anticipatory guidance with respect to screening tests and how their lives might ultimately be affected by having had cancer/treatment. Clinicians cannot assume that these issues were addressed at the end of treatment and, even if addressed, the information may not be recalled accurately by the now-adult survivor. Repetition and periodic reassessment of what the patient knows and understands is important for this population.

Finally, our findings provide evidence necessary to design and test potential interventions. For example, targeting demographic and diagnostic subgroups to raise need awareness and to address unmet needs are important intervention targets. Developing survivor support groups specifically for older survivors within long-term care models may be an important adjunct to care. Support groups for adolescents and young adults have been established with some success on web-based information sites and through clinical resources in selected communities [56]. It is not clear that these same options are in place for older adult survivors of pediatric malignancies; nor is it clear that older survivors would be receptive to web/electronic interventions. Interventions that would facilitate improved provider-survivor interaction and communication could be incorporated into LTFU staff training programs and offered to survivors through distance-based strategies [57].

Providers have been challenged to "address the needs of and provide hope for a valued future to those who have moved beyond a cancer diagnosis and into the role of survivor" [58]. There is growing recognition of the need for flexible models of care with multiple options to accommodate survivors' differing needs and circumstances. Systematically documenting adult childhood cancer survivors' needs as they age and building health-care infrastructures and interventions to address these needs are first steps toward creating models of excellence in survivorship care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Stratum-Specific Prevalence of Unmet Needs

Variable	Subgroup	Total (%)	Unmet Psycho-Emotional Needs (%)	Unmet Coping Needs (%)	Unmet Care/ Support Needs (%)	Unmet Health System Needs (%)	Unmet Cancer-Related information Needs (%)	Unmet Surveillance-related Needs (%)
Age at survey	26–35	391 (32.9)	172 (49.4)	121 (34.5)	98 (29.7)	124 (37.1)	200 (55.7)	123 (34.0)
	36–45	516 (43.4)	250 (55.4)	204 (44.0)	161 (37.3)	185 (41.9)	256 (56.5)	170 (36.0)
	46+	282 (23.7)	141 (57.1)	111 (43.9)	91 (38.4)	109 (44.1)	155 (59.6)	104 (40.2)
Sex	Male	465 (39.1)	200 (47.7)	142 (33.6)	113 (27.8)	145 (35.4)	213 (49.7)	134 (30.9)
	Female	724 (60.9)	363 (57.9)	294 (45.6)	237 (40.0)	273 (44.5)	398 (61.9)	263 (39.8)
Race	White	1057 (88.9)	509 (54.3)	392 (41.0)	313 (35.0)	374 (40.8)	542 (56.6)	350 (36.1)
	Black	28 (2.4)	11 (55.0)	9 (39.1)	8 (40.0)	11 (50.0)	14 (60.9)	9 (37.5)
	Hispanic	76 (6.4)	30 (46.9)	22 (33.3)	18 (29.5)	20 (33.3)	38 (57.6)	26 (35.6)
	Other	28 (2.4)	13 (54.2)	13 (54.2)	11 (47.8)	13 (52.0)	17 (68.0)	12 (44.4)
Partner status	Partnered	755 (63.6)	355 (52.2)	259 (37.7)	220 (33.7)	268 (40.5)	394 (56.8)	261 (37.0)
	Unpartnered	433 (36.4)	207 (56.7)	177 (46.5)	129 (37.3)	149 (41.3)	216 (57.3)	136 (35.1)
Residence	Urban	1005 (84.5)	478 (54.3)	371 (41.0)	298 (35.5)	353 (40.9)	515 (57.0)	332 (35.9)
	Rural	184 (15.5)	85 (51.2)	65 (39.6)	52 (32.7)	65 (40.6)	96 (56.8)	65 (38.5)
Diagnosis	Leukemia	401 (33.7)	181 (51.6)	145 (41.2)	113 (33.8)	138 (40.9)	207 (57.3)	146 (40.2)
	Central nervous system tumor	159 (13.4)	67 (52.3)	62 (43.4)	37 (30.8)	56 (41.8)	64 (46.0)	40 (27.6)
	Hodgkin lymphoma	151 (12.7)	87 (62.6)	65 (48.5)	58 (45.0)	73 (54.9)	94 (68.6)	60 (42.9)
	Non Hodgkin lymphoma	88 (7.4)	46 (59.7)	30 (35.7)	24 (30.0)	31 (39.2)	48 (56.5)	20 (24.4)
	Wilms	121 (10.2)	47 (44.3)	32 (29.1)	26 (24.5)	31 (30.7)	56 (52.3)	38 (33.0)
	Neuroblastoma	76 (6.4)	36 (49.3)	26 (36.1)	19 (28.4)	25 (37.3)	43 (62.3)	25 (35.7)
	Soft-tissue Sarcoma	107 (9.0)	51 (52.0)	38 (40.0)	41 (45.6)	36 (37.9)	49 (52.7)	34 (35.1)
	Bone cancer	86 (7.2)	48 (64.9)	38 (48.7)	32 (43.8)	28 (36.4)	50 (61.7)	34 (42.0)
Chemotherapy	Yes	856 (76.5)	414 (55.0)	329 (42.6)	257 (35.5)	303 (40.9)	455 (58.7)	302 (38.4)
	No	263 (23.5)	111 (47.4)	83 (35.0)	64 (30.0)	92 (39.8)	119 (50.4)	66 (27.2)
Radiation	Yes	730 (65.0)	353 (56.6)	300 (46.4)	231 (38.4)	274 (44.5)	393 (60.4)	250 (37.5)
	No	393 (35.0)	175 (47.7)	114 (31.3)	91 (26.8)	120 (33.5)	184 (50.7)	121 (32.9)
Surgery	Yes	895 (80.0)	422 (53.8)	329 (40.8)	258 (34.3)	316 (40.8)	459 (56.7)	289 (35.1)

Variable	Subgroup	Total (%)	Unmet Psycho-Emotional Needs (%)	Unmet Coping Needs (%)	Unmet Care/ Support Needs (%)	Unmet Health System Needs (%)	Unmet Cancer-Related information Needs (%)	Unmet Surveillance-related Needs (%)
	No	224 (20.0)	103 (50.7)	83 (40.9)	64 (34.6)	79 (40.1)	114 (56.7)	80 (38.6)
Years since diagnosis	24–27	311 (26.2)	153 (55.8)	116 (41.3)	93 (35.6)	114 (43.5)	166 (59.7)	107 (36.6)
	28–31	295 (24.8)	142 (54.6)	107 (41.3)	89 (35.2)	100 (38.8)	152 (56.3)	97 (36.5)
	32–35	293 (24.6)	143 (55.2)	112 (41.8)	90 (35.6)	100 (39.2)	156 (58.4)	93 (34.3)
	36–42	290 (24.4)	125 (49.4)	101 (38.8)	78 (33.6)	104 (41.9)	137 (53.3)	100 (37.9)
Age at diagnosis	0–4	452 (38.0)	197 (48.9)	142 (35.1)	118 (31.2)	146 (37.4)	226 (55.4)	147 (35.3)
	5–9	271 (22.8)	131 (56.0)	103 (42.4)	72 (32.7)	93 (41.2)	132 (55.2)	87 (36.1)
	10–14	247 (20.8)	110 (52.1)	92 (41.4)	82 (38.9)	89 (42.2)	126 (56.8)	87 (37.7)
	15–20	219 (18.4)	125 (63.1)	99 (49.7)	78 (41.1)	90 (45.9)	127 (62.6)	76 (37.1)
CTCAE (Chronic disease grade)	0(none)	283 (23.8)	116 (44.6)	70 (26.8)	52 (20.8)	76 (30.2)	119 (45.8)	75 (28.1)
	1(mild)	255 (21.4)	114 (52.1)	96 (42.1)	73 (34.9)	86 (40.8)	134 (59.3)	86 (37.1)
	2(moderate)	303 (25.5)	157 (58.1)	126 (47.0)	103 (39.9)	124 (46.1)	176 (63.1)	122 (44.0)
	3(severe/disabling)	200 (16.8)	104 (59.8)	83 (44.6)	73 (44.8)	73 (44.2)	101 (57.1)	72 (38.3)
	4(life-threatening)	148 (12.4)	72 (58.5)	61 (48.8)	49 (41.2)	59 (46.8)	81 (62.3)	42 (32.6)
Education	1–8 y	1 (0.1)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)	1 (100.0)	1 (100.0)
	9–12 y	4 (0.3)	4 (100.0)	2 (66.7)	4 (100.0)	3 (75.0)	4 (100.0)	2 (50.0)
	High School/GED	87 (7.3)	38 (52.8)	36 (47.4)	26 (40.0)	27 (41.5)	42 (59.2)	29 (37.7)
	Technical Training	43 (3.6)	21 (53.8)	11 (28.9)	12 (32.4)	16 (42.1)	20 (50.0)	14 (35.9)
	Some college	175 (14.8)	79 (52.3)	62 (39.5)	52 (36.4)	65 (43.0)	81 (50.6)	52 (32.1)
	Degree	517 (43.6)	234 (52.3)	186 (40.3)	149 (34.4)	160 (36.0)	251 (54.6)	160 (34.4)
	Post graduate	347 (29.3)	178 (56.0)	128 (40.5)	102 (33.8)	142 (46.3)	203 (63.0)	133 (40.2)
	Other	11 (0.9)	6 (60.0)	8 (72.7)	4 (36.4)	4 (44.4)	8 (72.7)	6 (60.0)
Annual household income	<$39,999	260 (24.1)	147 (64.8)	106 (47.1)	82 (40.8)	104 (49.1)	132 (57.9)	97 (41.5)
	$40,000 –$59,999	198 (18.4)	94 (53.7)	82 (46.3)	70 (41.4)	76 (43.9)	100 (54.3)	59 (32.8)
	$60,000 – $99,999	307 (28.5)	128 (46.2)	99 (35.1)	77 (28.5)	98 (35.5)	162 (58.5)	106 (36.3)
	>$100,000	312 (29.0)	153 (54.1)	111 (38.0)	87 (31.8)	107 (38.9)	171 (58.2)	103 (35.4)
Employment	Full-time	728 (62.2)	325 (49.1)	239 (35.8)	184 (29.4)	241 (37.7)	374 (55.6)	237 (34.8)
	Part-time	136 (11.6)	67 (59.3)	53 (44.2)	51 (44.7)	52 (43.0)	69 (55.6)	53 (42.1)
	Unemployed	69 (5.9)	36 (59.0)	35 (56.5)	26 (44.1)	23 (40.4)	34 (55.7)	22 (34.9)

Variable	Subgroup	Total (%)	Unmet Psycho-Emotional Needs (%)	Unmet Coping Needs (%)	Unmet Care/Support Needs (%)	Unmet Health System Needs (%)	Unmet Cancer-Related information Needs (%)	Unmet Surveillance-related Needs (%)
	Disability	102 (8.7)	61 (79.2)	54 (65.1)	44 (57.9)	48 (64.0)	58 (67.4)	37 (43.5)
	Other	136 (11.6)	64 (54.7)	49 (41.2)	42 (37.2)	51 (43.2)	69 (60.0)	48 (39.0)
Health Insurance	Yes	1078 (91.9)	510 (53.6)	387 (40.1)	313 (34.2)	375 (40.4)	559 (57.2)	355 (35.8)
	No	95 (8.1)	43 (53.1)	38 (43.7)	31 (42.5)	39 (46.4)	46 (55.4)	36 (40.9)
Concern re: future cancer	None/not very	467 (39.6)	166 (39.5)	134 (30.9)	104 (25.4)	118 (28.9)	190 (44.7)	123 (27.8)
	Somewhat, very	713 (60.4)	392 (63.4)	301 (48.0)	245 (42.0)	298 (49.0)	417 (65.2)	272 (42.3)
Anxiety/fear re: cancer/treatment	None/small amount	1014 (85.9)	442 (48.8)	340 (36.6)	262 (30.1)	320 (36.1)	488 (53.0)	315 (33.4)
	Medium/extreme	167 (14.1)	120 (88.2)	96 (71.6)	87 (69.0)	98 (74.2)	121 (82.3)	81 (55.9)
Concern about future health	Not at all/not very much	376 (31.8)	136 (38.7)	101 (28.5)	71 (20.8)	88 (25.9)	146 (42.4)	106 (29.5)
	Somewhat, very much	808 (68.2)	425 (61.6)	334 (47.2)	278 (42.5)	330 (48.5)	463 (64.0)	290 (39.8)
Concern about having children	Not at all/not very much	867 (73.4)	385 (50.5)	303 (38.4)	243 (32.9)	281 (37.5)	425 (53.9)	276 (34.5)
	Somewhat, very much	314 (26.6)	175 (63.2)	132 (48.7)	106 (41.4)	136 (50.6)	183 (66.1)	119 (41.8)
Concern about health insurance	Not at all/not very much	757 (64.2)	317 (46.8)	226 (32.8)	179 (27.4)	226 (33.7)	357 (51.7)	229 (32.5)
	Somewhat, very much	422 (35.8)	243 (67.5)	209 (56.3)	170 (50.3)	191 (55.2)	252 (67.4)	167 (43.9)
Health status	Excellent	192 (16.4)	60 (34.7)	42 (23.3)	37 (22.0)	46 (27.9)	82 (46.3)	56 (30.9)
	Very good	469 (40.1)	226 (52.9)	167 (38.8)	132 (32.0)	164 (39.0)	235 (54.8)	161 (36.3)
	Good	375 (32.1)	193 (60.5)	161 (48.8)	121 (39.9)	153 (47.7)	214 (63.3)	131 (38.8)
	Fair	111 (9.5)	60 (65.9)	49 (53.3)	45 (54.2)	37 (45.1)	57 (61.3)	33 (35.1)
	Poor	23 (2.0)	15 (78.9)	13 (65.0)	11 (61.1)	13 (72.2)	13 (72.2)	14 (66.7)
Care location	Other places	1005 (84.8)	462 (52.1)	352 (38.7)	280 (32.7)	347 (39.6)	499 (54.8)	330 (35.4)
	Oncology/Long-term follow-up clinic	180 (15.2)	98 (63.2)	82 (52.9)	68 (48.6)	70 (49.0)	109 (69.0)	66 (41.8)

Table 2

Care/Support and Coping Needs

A. Care/Support	Covariates									
Needs	**Hodgkin Lymphoma**	**CNS Tumor**	**Leukemia/NHL**	**Health status: (good/fair/poor)**	**CTCAE (grade 3, 4)**	**Radiation**	**Chemotherapy**	**Oncology Clinic LTFU**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Having insurance**	**Concern re: Having children**
1. Seeing specialists	1.72 (1.01–2.91)			1.51 (1.03–2.22)		1.79 (1.20–2.66)	1.72 (1.01–2.91)		2.72 (1.71–4.33)	2.33 (1.59–3.42)	1.56 (1.06–2.29)
2. Reducing late effects						1.77 (1.22–2.56)	1.79 (1.08–2.95)		2.47 (1.57–3.91)	2.53 (1.76–3.64)	1.74 (1.21–2.49)
3. Knowing who to call						1.62 (1.09–2.39)	2.17 (1.24–3.80)		3.39 (2.12.–5.45)	1.84 (1.22–2.76)	2.25 (1.54–3.30)
4. Getting providers to be sensitive		1.84 (1.09–3.13)			1.57 (1.03–2.41)	1.67 (1.09–2.54)	2.49 (1.38–4.51)		4.11 (2.52–6.71)	2.36 (1.55–3.59)	1.56 (1.03–2.36)
5. Getting HDD to see my viewpoint						1.90 (1.23–2.96)			4.18 (2.52–6.93)	2.95 (1.87–4.66)	1.68 (1.11–2.56)
6. Getting MD to answer questions		1.77 (1.00–3.14)				1.80 (1.13–2.87)			2.39 (1.42–4.03)	2.33 (1.43–3.65)	
7. Asking tor choices/ options						1.97 (1.27–3.06)	2.82 (1.49–5.36)		3.72 (2.25–6.13)	2.28 (1.47–3.54)	1.53 (1.01–2.33)
8. Getting reassurance	1.84 (1.05–3.22)				1.90 (1.25–2.89)	2.21 (1.42–3.45)	2.80 (1.55–5.04)		3.01 (1.85–4.89)	2.11 (1.39–3.18)	
9. Getting honesty from medical staff					1.86 (1.16–2.98)	1.84 (1.15–2.95)			2.99 (1.77–5.04)	2.11(1.33–3.37)	1.72 (1.10–2.67)
10. Sharing feelings with MD					2.00 (1.23–3.24)	2.51 (1.43–4.26)		1.75 (1.02–3.01)	2.52 (1.46–4.35)	2.18 (1.34–3.52)	1.65 (1.04–2.61)
11. Having MD to care about me		2.45 (1.28–4.71)	1.83 (1.07–3.13)			1.97 (1.16–3.35)			3.12 (1.78–5.46)	2.12 (1.28–3.50)	1.72 (1.07–2.78)
12. Getting MD to encourage questions					1.92 (1.18–3.14)	2.63 (123–4.53)	3.57 (1.73–7.34)		3.01 (1.74–5.21)	1.87 (1.15–3.03)	
13. Getting MD to listen to me		2.01 (1.09–3.68)				1.77 (1.08–2.91)	2.72 (1.33–5.57)		2.51 (1.45–4.35)	2.04 (1.25–3.31)	1.59 (1.00–2.51)
14. Getting clinic appts						1.66 (1.02–2.69)			2.14 (1.22–3.74)	2.21 (1.36–3.57)	
15. Getting medical requests answered					1.67 (1.01–2.75)	1.86 (1.14–3.03)			4.28 (2.51–7.30)	2.24 (1.36–3.68)	1.64 (1.03–2.61)
16. Hating more say in decisions						1.86 (1.14–3.03)	2.03 (1.04–3.95)		3.06 (1.77–5.27)	2.43 (1.50–3.95)	
17. Having MD to consider my views		2.24 (1.13–4.41)	2.17 (1.27–3.70)			2.00 (1.18–3.38)			2.20 (1.23–3.92)	2.84 (1.71–4.72)	
18. Having more trust in MD	2.03 (1.06–3.88)			1.71 (1.01–2.89)		1.87 (1.09–3.21)			3.12 (1.76–5.52)	2.40 (1.42–4.03)	

A. Care/Support				**Covariates**							
Needs	**Hodgkin Lymphoma**	**CNS Tumor**	**Leukemia/NHL**	**Health status: (good/fair/poor)**	**CTCAE (grade 3, 4)**	**Radiation**	**Chemotherapy**	**Oncology Clinic LTFU**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Having insurance**	**Concern re: Having children**
19. Getting MD to be confident in my choices		2.59 (1.29–5.20)				2.56 (1.37–4.79)			2.80 (1.43–5.30)	2.05 (1.15–3.67)	
20. Getting MD to be accepting						4.57 (2.01–10.36)	3.05 (1.25–7.40)		3.88 (1.97–7.66)	2.79 (1.44–5.43)	

B. Coping Needs							
	Hodgkin Lymphoma	**Health status: (good/fair/poor)**	**Radiation**	**Oncology Clinic LTFU**	**Concern re: Cancer returning**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Health insurance**
1. Emotional support			1.60 (1.09–2.33)			3.26 (2.05–5.19)	2.32 (1.58–3.41)
2. Talk with someone who understands			2.12 (1.48–3.05)	1.76 (1.16–2.66)		3.23 (2.05–5.10)	2.09 (1.46–2.99)
3. Talk with others about cancer			1.80 (1.23–2.61)	1.65 (1.08–2.53)	1.53 (1.03–2.25)	2.80 (1.77–4.45)	1.96 (1.35–2.84)
4. Coping with future	1.71 (1.05–2.81)		1.54 (1.07–2.23)			3.19 (2.01–5.06)	2.38 (1.64–3.45)
5. Body image issues		1.49 (1.05–2.12)	1.60 (1.12–2.28)		1.58 (1.08–2.31)	2.41 (1.53–3.81)	2.31 (1.63–3.28)
6. Adjusting to changes in body		1.83 (1.24–2.70)	1.72 (1.16–2.56)	1.57 (1.00–2.45)	2.38 (1.51–3.75)	2.48 (1.53–4.04)	2.83 (1.92–4.16)
7. Making decisions about life		1.58 (1.04–2.42)	1.86 (1.23–2.81)	1.65 (1.03–2.62)		3.70 (2.26–6.04)	2.15 (1.41–3.27)
8. Feeling loss of emotional control		1.99 (1.31–3.01)	1.60 (1.07–2.40)			5.07 (3.15–8.16)	2.43 (1.61–3.67)
9. Making sense of illness		1.87 (1.21–2.91)				4.14 (2.51–6.81)	1.95 (1.26–3.02)
10. Moving on with life		2.23 (1.41–3.52)	1.59 (1.03–2.47)			5.56 (3.34–9.25)	2.09 (1.33–3.29)
11. Trying to make life count		1.78 (1.16–2.74)				3.74 (2.27–6.15)	2.55 (1.66–3.92)
12. How I feel as man/woman		1.68 (1.05–2.70)				2.72 (1.58–4.67)	2.09 (1.30–3.34)

Abbreviations: CNS, central nervous system; NHL non-hodgkins Lymphoma; CTCAE, Common Terminology Criteria for Adverse Events; LTFU, long-term follow-up

Table 3

Psycho-Emotional Needs and Associated Factors

	Covariates								
Needs	**Hodgkin Lymphoma**	**CNS tumor**	**Leukemia/NHL**	**Health status (good/fair/poor)**	**CTCAE (grade 3, 4)**	**Radiation**	**Oncology Clinic LTFU**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Health insurance**
1. Worry						1.59 (1.17–2.16)		6.06 (3.79–9.69)	1.65 (1.19–2.29)
2. Uncertainty about future	1.77 (1.13–2.78)			1.68 (1.21–2.33)	1.42 (1.01–1.99)	1.84 (1.34–2.51)		5.50 (3.44–8.77)	1.74 (1.25–2.42)
3. Anxiety	1.62 (1.04–2.53)			1.52 (1.10–2.11)		1.64 (1.21–2.23)		6.10 (3.82–9.72)	1.44 (1.03–2.00)
4. Reducing stress				1.87 (1.36–2.59)				3.39 (2.19–5.25)	1.78 (1.28–2.46)
5. Feeling down depressed	1.73 (1.10–2.71)			1.51 (1.10–2.08)		1.44 (1.06–1.95)		4.62 (2.95–7.24)	1.75 (1.27–2.42)
6. Feeling nervous/afraid/tense				1.70 (1.22–2.38)		1.61 (1.16–2.23)		4.50 (2.91–6.96)	1.43 (1.02–2.01)
7. Feeling calm and peaceful				1.71 (1.21–2.41)	1.50 (1.05–2.13)	1.55 (1.11–2.18)	1.61 (1.04–2.48)	3.67 (2.37–5.68)	1.60 (1.14–2.27)
8. Maintaining a positive outlook		1.66 (1.04–2.64)		1.71 (1.18–2.46)		1.69 (1.18–2.42)	1.60 (1.01–2.52)	3.97 (2.55–6.21)	1.83 (1.27–2.63)
9. Fears about physical disability				2.19 (1.54–3.11)	1.76 (1.23–2.51)	1.78 (1.26–2.52)	1.62 (1.04–2.53)	3.47 (2.21–5.46)	1.97 (1.38–2.80)
10. Feeling angry				1.58 (1.11–2.24)		1.42 (1.01–2.00)		3.25 (2.12–5.01)	1.59 (1.12–2.26)
11. Loss of control over emotions								3.46 (2.20–5.43)	
12. Fears about pain				2.46 (1.67–3.63)		1.47(1.02–2.14)		3.84 (2.44–6.05)	1.88(1.28–2.77)
13. Feeling in control		1.62 (1.01–2.61)		2.85 (1.95–4.17)	1.47 (1.01–2.15)	1.57(1.08–2.27)	1.63 (1.02–2.60)	4.19 (2.63–6.66)	1.85 (1.27–2.71)
14. Changes to usual routine/lifestyle		1.91 (1.14–3.19)	1.50 (1.00–2.25)	1.59 (1.06–2.37)		1.79 (1.20–2.66)	1.62 (1.01–2.60)	3.31 (2.07–5.29)	1.76 (1.18–2.63)
15. Making the most of my time								2.85 (1.75–4.63)	2.16 (1.43–3.26)
16. Dealing with feeling bored/useless		1.82 (1.06–3.13)		1.58 (1.04–2.38)	1.53 (1.00–2.34)	1.70 (1.11–2.61)	1.65 (1.01–2.70)	1.86 (1.12–3.08)	1.57 (1.04–2.37)

Abbreviations: CNS, central nervous system; NHL, non-hodgkins lymphoma; CTCAE, Common Terminology Criteria for Adverse Events; LTFU, long-term follow-up

Table 4

Cancer-Related Information, Health Systems Concerns and Surveillance-Related Information

A. Cancer-Related Information Needs											
	Covariates										
Needs	**CNS Tumor**	**Hodgkin Lymphoma**	**Health status (good/fair/poor)**	**Leukemia/NHL**	**Radiation**	**Chemotherapy**	**Oncology Clinic LTFU**	**Concern re: Cancer returning**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Health insurance**	**Concern re: Having children**
1. Late effects	0.50 (0.33–0.78)	1.99 (1.27–3.11)			1.51 (1.13–2.02)	2.09 (1.39–3.14)	1.79 (1.19–2.70)	1.41 (1.05–1.91)	3.21 (2.00–5.17)	1.70 (1.24–2.31)	1.70 (1.24–2.33)
2. How cancer affected my body	0.58 (0.38–0.90)		1.61 (1.19–2.19)		1.49 (1.11–1.99)			1.41 (1.04–1.90)	2.82 (1.80–4.44)	1.62 (1.18–2.21)	1.63 (1.20–2.23)
3. Which organ systems may have been affected	0.62 (0.40–0.96)	1.77 (1.14–2.76)	1.42 (1.04–1.92)		1.44 (1.07–1.93)	1.74 (1.16–2.63)		1.59 (1.17–2.17)	2.96 (1.89–4.62)		1.55 (1.13–2.12)
4. Specific disease that can result from cancer therapy		1.86 (1.20–2.90)	1.40 (1.04–1.90)		1.53 (1.14–2.04)	1.73 (1.15–2.61)		1.43 (1.06–1.94)	2.55 (1.64–3.97)	1.60 (1.17–2.18)	1.39 (1.02–1.90)
5. What I can do to reduce my chances of developing late effects	0.59 (0.38–0.92)		1.37 (1.01–1.85)		1.45 (1.08–1.94)	1.64 (1.09–2.46)		1.41 (1.04–1.91)	2.91 (1.85–4.57)	1.69 (1.24–2.31)	1.43 (1.04–1.96)
6. How cancer will affect my life		1.79 (1.13–2.82)	1.47 (1.07–2.01)	1.63 (1.19–2.23)	1.51 (1.11–2.06)	1.60 (1.04–2.47)			2.53 (1.64–3.90)	1.69 (1.23–2.33)	1.65 (1.19–2.28)
7. Cancer recurrence								1.71 (1.25–2.35)	2.21 (1.45–3.37)	1.51 (1.10–2.08)	1.53 (1.12–2.10)
8. My treatments/medications					1.51 (1.10–2.09)	1.58 (1.01–2.48)			2.67 (1.74–4.10)		
9. What symptoms to report									2.26 (1.48–3.46)		
10. What causes cancer					1.52 (1.09–2.11)				2.69 (1.74–4.16)	1.61 (1.15–2.26)	
11.·My test results as soon as possible		1.96 (1.18–3.25)		1.47 (1.00–2.15)	1.74 (1.20–2.53)				2.97 (1.87–4.71)	2.17 (1.50–3.14)	1.48 (1.01–2.18)

B. Health Systems Information Needs										
	Hodgkin Lymphoma	**CNS Tumor**	**Health status (good/fair/poor)**	**CTCAE (grade 3, 4)**	**Radiation**	**Oncology Clinic LTFU**	**Concern re: Cancer returning**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Health insurance**	**Concern re: Having children**
1. Important aspects of my after-cancer care	1.65 (1.04–2.63)				1.48 (1.06–2.06)			2.74 (1.78–4.23)	1.93 (1.38–2.70)	1.47(1.05–2.07)
2. My doctors to talk to each other to	1.92 (1.17–3.14)				1.70 (1.19–2.45)			3.68 (2.35–5.76)	1.83 (1.27–2.63)	1.78 (1.23–2.57)

B. Health Systems Information Needs										
	Hodgkin Lymphoma	**CNS Tumor**	**Health status (good/fair/poor)**	**CTCAE (grade 3, 4)**	**Radiation**	**Oncology Clinic LTFU**	**Concern re: Cancer returning**	**Moderate/Extreme: Cancer-related anxiety**	**Concern re: Health insurance**	**Concern re: Having children**
coordinate my care										
3. One health care provider with whom I could talk about my health								2.56 (1.63–4.04)		1.67 (1.17–2.40)
4. Help to know how to give input to my medical team in order to manage my health					1.81 (1.22–2.69)			3.24 (2.03–5.18)	1.82 (1.23–2.71)	1.87 (1.26–2.78)
5. Information about whom to call for help					1.61 (1.09–2.39)			2.82 (1.77–4.51)	1.65 (1.11–2.43)	2.18 (1.49–3.20)
6. Choices about when to go in for check-ups					1.52 (1.02–2.26)		1.62 (1.05–2.50)	2.67 (1.64–4.34)		
7. My complaints about my care heard and addressed				1.70 (1.11–2.60)	1.68 (1.12–2.54)			2.63 (1.61–4.29)	1.99 (1.32–3.00)	
8. To be treated like a person, not just another case		1.77 (1.02–3.08)		2.33 (1.51–3.59)		1.92 (1.16–3.16)		2.74 (1.65–4.54)	2.06 (1.35–3.16)	
9. Help finding access to professional counseling								2.56 (1.59–4.12)	1.49 (1.01–2.20)	
10. Information about support groups in my area	2.07 (1.18–3.61)		1.52 (1.01–2.29)	1.62 (1.07–2.47)	1.52 (1.01–2.30)			2.40 (1.48–3.90)		1.53 (1.02–2.30)

C. Surveillance-Related Information Needs									
	CNS tumor	**Hodgkin Lymphoma**	**Leukemia/NHL**	**Radiation**	**Chemotherapy**	**Moderate/Extreme cancer-related anxiety**	**Concern re: Cancer returning**	**Concern re: Health Insurance**	**Concern re: Having Children**
1. What screening tests I need based on treatment history	0.55 (0.34–0.91)					2.86 (1.85–4.41)	1.47 (1.05–2.05)	1.42(1.02–1.99)	
2. Which tests will help detect late effects of treatment		1.65 (1.02–2.67)	1.44 (1.04–2.01)		2.34 (1.44–3.82)	2.53 (1.63–3.92)	1.59 (1.13–2.25)	1.55 (1.11–2.18)	
3. Why screening tests need to be performed			1.52 (1.02–2.28)			2.66 (1.72–4.66)			
4. How screening tests are performed			1.63 (1.06–2.53)			2.66 (1.58–4.49)			
5. How I will feel during screening tests			1.55 (1.01–2.39)		1.92 (1.06–3.50)	3.31 (2.05–5.56)		1.53 (1.00–2.34)	
6. Info on how to prepare for screening tests						3.22 (1.93–5.36)	1.61 (1.02–2.56)		
7. How much time screening tests will take		1.85 (1.03–3.31)		1.61 (1.04–2.49)	2.30 (1.22–4.33)	2.43 (1.47–4.02)	1.75 (1.11–2.76)	1.71 (1.13–2.60)	1.58 (1.04–2.41)
8. Reducing responsibilities so that I can participate in screening			1.82 (1.17–2.84)			2.22 (1.31–3.75)	1.74 (1.09–2.76)	1.68 (1.09–2.59)	

Abbreviations: NHL, non-hodgkins lymphoma; LTFU, long-term follow-up

Abreviations: NHL, Non-hodgkin lymphoma; CTCAE, Common Terminology Criteria for Adverse Events, LTFU, long-term follow-up

Abbreviation; CNS: central nervous system; NHL, non-hodgkin lymphoma