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Reliability of Self-Reported Late Effects by Childhood Cancer Survivors and Caregivers: A Study of CHOA-CAYACSS

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Master of Public Health

Epidemiology

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Committee Chair

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Abstract

Reliability of Self-Reported Late Effects by Childhood Cancer Survivors and Caregivers: A Study of CHOA-CAYACSS

By Kelsey Rogowski

Introduction: The survival rate of childhood cancer has risen to over 80%; as of January 1, 2010, an estimated 379,112 survivors of childhood and adolescent cancer were alive in the United States. Research shows that survivors of childhood cancer are at increased risk for long-term complications due to treatments. Most research on late effects relies on self-reported data by childhood cancer survivors and caregivers. This analysis assesses the degree of agreement between medical records and self-reported surveys for certain late effects, as well as factors associated with reporting with high agreement.

Methods: CHOA-CAYACSS is an institutional longitudinal study evaluating health-related characteristics of a cohort of survivors of childhood cancer at Children's Healthcare of Atlanta's Cancer Survivor Program (CSP). We analyzed 244 patients who completed baseline surveys within 1 month of Cancer Survivor Follow-Up (CSFU) visits or between 1 and 15 months of Cancer Survivor (CS) or CSFU visits. Reported prevalence of late effects and agreement between survey report and medical records were determined for 12 late effects surveyed in CHOA-CAYACSS. Logistic regression was performed to determine the factors associated with having overall high agreement, defined as agreeing on 11 or more late effects.

Results: The sample agreed on a range of 9-12 of the 12 late effects comparing survey reports and medical records. Overall significant differences were found in reporting fatigue, hypothyroidism, asthma, and weak bones ($p<0.05$). Other thyroid problems, weak heart muscle, diabetes, and need for hormone replacement had Kappa ≥ 0.98. Controlling for diagnosis, survey type, sex, and visit count before baseline, surveys completed within 1 month of a CSFU visit were 5.44 times more likely to have high agreement than surveys completed between 12-15 months of visits [OR= 5.44 (95% CI: 1.17, 25.34)].

Discussion: This analysis supports a robust understanding of long-term complications in childhood cancer survivors that require the use of both medical records and self-report. By tailoring education and survivor visits to more closely fit the needs of survivors, CSP can better address and ameliorate each aspect of life affected by cancer treatments and provide comprehensive care for childhood cancer aging and transitioning into adulthood.

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Background and Introduction

Incidence

The incidence rate of pediatric cancer has been increasing since 1975, with a current incidence rate of 186.6 per 1 million children and adolescents aged 0 to 19 years. According to SEER data and US census records, an estimated 15,880 new childhood and adolescent cancer cases were projected to be diagnosed in 2014 in the United States (1). This is equal to, on average, 1 in 408 children aged 0-14 being diagnosed with cancer, and 1 in 285 children being diagnosed with cancer before age 20 years. For children born in the United States, children have a 0.24% chance of being diagnosed with cancer before age 15 years, and a 0.35% chance of being diagnosed with cancer before age 20 years (1).

Types of Childhood Cancers

Childhood cancers represent roughly 1% of all new cancer cases in the United States (1). However, the most common specific types of childhood cancers that affect this 0-19 year population differ between childhood (0-14 years) and adolescence (15-19). The four most common types of cancer for children 0-14 years are acute lymphocytic leukemia (ALL) (26%), brain and central nervous system (CNS) tumors (21%), neuroblastomas (7%) and non-Hodgkin lymphoma (6%). The four most common cancers diagnosed in adolescents are Hodgkin lymphoma (15%), thyroid carcinoma (11%), brain and CNS tumors (10%) and testicular germ cell tumors (8%) (1).

Epidemiology of Childhood Cancers

The epidemiology and etiology of childhood cancers is not well established. However, it has been shown that there are distinct differences between the incidences of each type of childhood cancer. Overall, males have a higher rate for developing childhood and adolescent cancers than females, but have a similar observed survival rate

(males (0-14) 78.0 per 1 million, females (0-14) 160.1 per 1 million; survival ~80%). In the adolescent population, this finding of varying incidence rate is attenuated, as boys have a slightly higher rate of developing cancer than females (237.7 per 1 million v. 235.5 per 1 million) (1). The observed survival in adolescents is similar to children, with survival percentages ranging from 80.0% to just over 85.0%. However, survival in adolescence is higher for girls than for boys, and this may be attributed to the different types of cancers that occur in boys compared to girls in this age group (1).

Cancer incidence, survival, and mortality rates also vary by race and ethnicity. Non-Hispanic whites have the highest incidence rates for childhood and adolescent cancers, but in turn also have the highest observed survival around 84-85% (1). Hispanics have the second highest incidence rates of both children and adolescents, with observed survival at 80.3% for children and 75.8% for adolescents. Other race and ethnicity groups, such as Non-Hispanic blacks and Asian/Pacific Islanders have similar incidence rates during both childhood and adolescence. American Indians/Alaskans have the lowest incidence rates in childhood, but have the third highest incidence rate in adolescence (1).

There are relatively few known preventable causes of childhood cancer, which is a stark contrast to the well-known etiology of adult cancers. Ionizing radiation exposure is a highly supported risk factor for leukemia and other cancers for children and adolescents since the 1950s (2). For instance, for the most common type of childhood cancer, acute lymphocytic leukemia (ALL), risk factors with supporting evidence include male gender, Hispanic origin, certain genetic syndromes, such as Trisomy 21, and monozygotic twins. Environmental and lifestyle factors, such as higher birth weight have

been associated with a higher risk of ALL (1, 3, 4). As well, ALL is more common in industrialized countries than in developing countries (5).

Why Survivorship

An estimated 379,112 survivors of childhood and adolescent cancer were alive in the United States as of January 1, 2010 (1). With the growing number of adult survivors in the general population, steps must be taken to ensure the continuing health needs of this unique and vulnerable population as they age (6-8). Previous research has shown that survivors of childhood cancer are at an increased risk for long-term complications due to various treatments for cancer diagnoses. Issues that must be monitored include medical late effects, secondary malignancies, prevention of risky health behaviors, and psychosocial and quality of life difficulties (9-11). By quantifying the prevalence of these late effects and their correlation to specific treatments, we can continue to improve surveillance techniques to ameliorate the impact that these potentially severe and disabling complications can have on survivors' lives (12).

Prevalence and Risk Factors of Late Effects

Due to the multi-modal approaches to treating childhood and adolescent cancer, a variety of unrecognized toxicities are manifesting years after treatment in these cancer survivors (8-10, 13, 14). Late effects vary person to person and have risk factors associated with treatment, genetics, and other environmental or behavioral factors. As well, these late effects differ in the magnitude of debilitation that they may impose on the survivor (10).

Of the various medical and psychosocial late effects appearing in the survivor population, adverse health outcomes such as pulmonary, auditory, endocrine or

reproductive, cardiac, and neurocognitive impairments were the most prevalent in a study of adult survivors of childhood cancer with a median age of 32 years (8). According to Mertens et al., a retrospective analysis of 20,227 5-year survivors found statistically significant excess rates of death from secondary neoplasms, cardiac causes, and pulmonary causes (15). Hudson et al. found in a study of 9,535 adults who had survived childhood cancer, 44% reported the presence of at least one adversely affected health status domain, including general health (10.9%), mental health (17.2%), functional impairment (12.0%), activity limitations (12.5%), cancer-related pain (10.2%), and cancer-related fear or anxiety (13.2%) (16). Oeffinger et al. found in an analysis of 10,397 adult survivors of childhood cancer and 3,034 siblings that 62.3% of survivors reported at least one chronic health condition, with 27.5% reporting a severe or life-threatening or disabling condition, compared to 36.8% of siblings reporting any chronic health condition, of which 5.2% were considered severe or life-threatening (9).

Previous Literature of Reporting of Late Effects

The majority of the current research on late effects of treatment relies on self-reported data by childhood cancer survivors and their caregivers (17). Due to this, it is not well established how reliable these techniques are in supporting the continual update of long-term follow-up guidelines for survivors. Thus, studies must be done to show the agreement between these self-reported surveys and medical records in assessing reliability. Few studies have been reported previously that assess the validity of self-reported long-term complications in childhood cancer survivors. An analysis of 153 survivors and parents in the United Kingdom found that both survivors and parents reported more late effects than documented in medical records. These findings were

especially significant in general problems, such as mood swings, learning problems, and weight gain (18). Additionally, an analysis of 100 patients who had undergone bone marrow transplantation had intermediate to excellent agreement (Kappa = 0.4-1.0) with the gold standard medical records for all complications evaluated, such as ocular, endocrine, cardiovascular, musculoskeletal, pulmonary, gastrointestinal, neurological, graft-versus-host disease, and subsequent cancers (17).

By looking at the various factors that may contribute to an increased agreement between reports by surveys and medical record reports, we can create a representative model to quantify these relationships. The aim of this analysis was to determine the degree of agreement between medical record and childhood cancer survivors or caregivers for reports of therapy-related, long-term complications. As well, the study aimed to determine the factors related to reporting with high agreement for survey respondents and medical records on various late effects.

Methods

Patient Population

The Cancer Survivor Program (CSP) at Children's Healthcare of Atlanta was developed to serve cancer survivors' specialized, long-term healthcare needs. Patients are eligible to attend the CSP at 2 years off-therapy for an initial Cancer Survivor (CS) consult and are advised to return yearly for screenings and management of late effects through Cancer Survivor Follow-Up (CSFU) visits. These annual visits include an assessment completed by a multidisciplinary team, a physical exam, and surveillance tests according to the Children's Oncology Group Long-Term Follow-Up Guidelines (COG-LTFU) (12). As well, specialized treatment summaries are provided as a resource

for patients, families, and providers to be educated on the possible late effects due to each treatment regimen. These summaries contain diagnosis/treatment details, an individualized risk profile with late effect screening guidelines, and current and previous test results combined in a Survivor Healthcare Plan (SHP) that is consistently updated and distributed to patients. As well, treatment information, visit data, and a medical problem list are maintained in a survivor database (12).

CHOA-CAYACSS (19): The Children's Healthcare of Atlanta – Childhood, Adolescent, and Young Adult Cancer Survivor Study (CHOA-CAYACSS) is an institutional longitudinal study conducted to evaluate health-related characteristics of a cohort of survivors of childhood cancer at the CSP (19). Inclusion criteria for participation in CHOA-CAYACSS is a diagnosis of a confirmed malignancy, or a non-malignant condition that is treated with cancer-like therapy at an age of ≤ 30 years of age. Survivors ≥ 18 years of age complete the questionnaire whereas caregivers of survivors < 18 years complete the annual report of health outcomes. Survey responses by survivors ≥ 18 years were considered survivor report, whereas survey responses for surveys < 18 years were considered parent or caregiver report. Enrollment in CHOA-CAYACSS began in January 2008 and has continued until present, with responses eligible for this analysis ending December 31, 2014 (19).

Inclusion criteria for analysis include those outlined in CHOA-CAYACSS, as well as currently living and completion of baseline survey before the 22nd birthday. For the final analysis, surveys that were completed within 1 month of a CSFU visit (n=96) or between 1 month and 15 months of a CS or CSFU visit (n=148) were included. Initial exclusion criteria for analysis included: completed in 2015 (n=17), completed survey on

or after 22nd birthday (n=25), deceased (n=5), non-malignant conditions (n=10), not complete surveys (n=3), withdrawn consent (n=1), and survey date of completion missing (n=5). As well, exclusion was then categorized into two categories: reasons pertaining to a CS visit or reasons pertaining to a CSFU visit. Surveys that were completed before a CS visit (n=19), the same day as a CS visit (n=53), or within 1 month of a CS visit (n=99) were all excluded. As well, surveys that were completed the same day as a CSFU visit (n=160) or more than 15 months after a visit (n=24) were also excluded.

Data Collection

Data were collected by retrieving information from three sources: self-reported data from CHOA-CAYACSS, and medical record reports and demographics from the survivor database and medical record abstraction pertaining to the CSP visits. Demographics and self-reported late effects were obtained from baseline surveys in REDCap (Nashville, TN). Information from medical records was obtained using the Children's Healthcare of Atlanta electronic medical records in Epic (Madison, WI). Dates of clinic visits, demographics, and medical record progress notes and test results were obtained using medical record review. Data were abstracted from a clinic visit that was closest to and before the date of baseline survey completion. Institutional Review Board (IRB) approval was obtained through Emory University and CHOA.

Study Variables

The exposures of interest in the study were diagnosis category and time between visit and baseline survey. Diagnoses were broken down into 7 categories: leukemia, Hodgkin disease, non-Hodgkin lymphoma, kidney tumor, neuroblastoma, sarcoma, other. The other category included carcinoma, endocrine tumor, germ cell tumors, brain or

central nervous system tumors, histiocytosis, liver tumors, and retinoblastomas. Time between visit and baseline survey was isolated to 1 day after a clinic visit to 15 months after a clinic visit for completion of the baseline survey. These were initially categorized as survey completion within one month of clinic visit or survey completion more than one month after clinic visit. These categories were further divided into <1 month, 1-3 months, 3-6 months, 6-12 months, and 12-15 months.

Other control variables included survey type, sex, and number of visits before baseline survey. Survey type was divided into two categories: under 18 or 18+. Sex was categorized dichotomously, either male or female. Number of visits before baseline was categorized into three groups for final analysis: 1 visit, 2 visits, 3 or more visits. Additional variables for demographics include race/ethnicity, age at diagnosis, age at survey, and education status of the mother or father, if under 18, or of the survivor if over 18. Race/ethnicity was originally categorized by CHOA-CAYACSS in five categories: White,Non-Hispanic, Black, Non-Hispanic, Hispanic, Asian or Pacific Islander, or Other, but was modified to combine Asian or Pacific Islander and Other for analysis. Age at diagnosis and age at survey were classified into four year age groups: 0-4 years, 5-9 years, 10-14 years, 15-18 years, and for age at survey, 19-22 years. Education status was categorized by CHOA-CAYACSS as: did not finish high school, high school or GED, some college, college graduate, some graduate or professional school, graduate or professional (medical, law) school graduate, or do not know.

The visit date was defined as the last visit prior to survey completion. Thus, the time between visit and appointment was defined as the number of days or months in between the last clinic visit and the date of survey completion. This date was used to

obtain all relevant items and late-effect variables from medical records and CHOA-CAYACSS for assessing agreement. Agreement late effects included: hearing problems, trouble walking, fatigue, hypothyroid, other thyroid problems (hyperthyroidism and other thyroid problem), weak heart muscle (congestive heart failure or cardiomyopathy), other heart problems (high blood pressure, irregular heart rate or palpitations, other heart problems), asthma (or wheezing), chronic pain (any chronic pain), diabetes, hormone replacement, and weak bones (osteopenia or osteoporosis).

The primary outcome of interest was the degree of agreement. After analyzing the distribution of agreement overall, 77.9% of surveys had 11 or 12 items in agreement with medical records. Thus, the degree of agreement was dichotomized into high agreement (agreement of 11 or 12 items) vs. low agreement (agreement of 10 or fewer items).

Data Analysis

All statistical analyses were performed using SAS 9.4 (Cary, NC). A two-tailed p-value of ≤ 0.05 was considered significant for all tests. A X^2 test of independence was used to compare demographic variables. A Kappa statistic was calculated to determine the reliability of reporting study variables between medical records and survey report (20).

Logistic regression was used to determine the independent relationship between degree of agreement and diagnosis category, as well as time between visit and baseline survey completion and other confounding variables. Logistic regression with multiple exposures was then used to determine if there was a significant effect of diagnosis category and time between visit and baseline survey completion on degree of agreement, controlling for potential confounders (survey type, sex, and number of visits before

baseline survey). Interaction variables between both diagnosis category and time between visit and baseline survey completion with all control variables were created to assess interaction. An a priori decision was made to keep all confounders in the model following interaction assessment. Finally, the logistic regression model was used to determine if diagnosis and time between visit and baseline survey completion had a significant effect on the degree of agreement between medical records and survivor/caregiver report.

Results

Study Participation

Inclusion into study participation is outlined in Figure 1. Analyses were conducted at each exclusion point to provide comparisons to other groups and justification for proceeding forward with a more concise analysis. An initial sample of 665 baseline surveys were identified in the survey portal within REDCap. After an initial exclusion of 66, there were 599 patients who then were included in the sample. Dates of clinic visit closest to baseline survey completion as outlined before were then determined for these 599 patients. Of these, they were further categorized into three groups: excluded for reasons pertaining to CS visits (n=171), excluded for reasons pertaining to CSFU visits (n=184), and included for final analysis (n=244).

Descriptive statistics were then compared across the three groups for comparison. As shown in Table 1, chi-square comparisons across the groups were non-significant, with the exception of diagnosis, age at survey, and number of visits before baseline survey completion being significant. Comparisons of survey type, sex, race/ethnicity, English speaking at home, age at diagnosis, and education statuses were non-significant across categories. Due to the similarity of the three groups and the aim of the study, the

group excluded for reasons pertaining to CS visits and the group excluded for reasons pertaining to CSFU visits were excluded. Thus, the final group to be analyzed included 244 surveys completed within 1 month of a CSFU visit or within 1-15 months of either a CS or CSFU visit.

Descriptive Statistics

The final sample for analysis (n=244) was composed of 197 under 18 baseline surveys (80.74%) and 47 18+ baseline surveys (19.26%), seen in Table 2. The final sample is fairly equal number of males to females (51.64 % vs. 48.36%), predominantly white, non-Hispanic (72.43%), a previous leukemia diagnosis (47.13%), diagnosed at 0-4 years (62.30%), and has more than 2 visits before baseline survey (49.18%).

Agreement between Survey Report and Medical Records

Table 2 shows the differences between reports for late effects overall and stratified by survey type. In comparing overall agreement between survey report and medical record report, fatigue, hypothyroidism, asthma, and weak bones were statistically significant. Survivors had higher reports of fatigue than documented in medical records (13.11% vs. 5.74%, p=0.0006). Overall, survivors significantly underreported hypothyroidism, asthma, and weak bones. Survivors reported 17 cases of weak bones, whereas medical records showed 39 cases of weak bones (6.97% vs. 15.98%, p=0.0002).

In Figure 2, agreement of reporting of late effects by caregivers of survivors under the age of 18 show four significant differences. Caregivers were found to over report trouble walking (7.61% vs. 4.06%, p=0.0078) and fatigue (10.15% vs. 5.08%, p=0.0121). However, caregivers reported fewer instances of chronic pain (9.64% vs. 15.23%, p=0.0781) when compared to medical record reports. As well, caregivers reported less

than half of the amount of cases of weak bones as medical record reports (5.58% vs. 12.69%, p =0.0026).

The agreement of reporting late effects by survivors 18 years and older is shown in Figure 3. Significant differences were found in reporting of fatigue, asthma, and weak bones. There were more reports of fatigue by survivors than were reported in medical records (23.53% vs. 8.51%, p=0.0192). Survivors reported less cases of asthma (14.89% vs. 27.66%, p=0.0127) and weak bones (12.77% vs. 29.79%, p=0.0309) than were reported in medical records.

Agreement of late effects between survivors and caregivers compared to medical records was assessed using a positive agreement, disagreement, and negative agreement method in Table 4. Overall agreement for late effects was found to range between 80% and almost 100% agreement. Late effects with agreement higher than 95% include hypothyroidism (96.72%), other thyroid problems (99.59), weak heart muscle (97.13%), diabetes (99.18%), and need for male or female hormone replacement (98.36%). The late effects that had agreement lower than 90% include fatigue (88.52%), asthma (85.66%), chronic pain (80.74%) and weak bones (85.25%). The highest Kappa statistics were seen for other thyroid problems and diabetes (Kappa = 1.00), hormone replacement (Kappa = 0.99), and weak heart muscle (Kappa = 0.98). The lowest Kappa statistics were observed in asthma (Kappa = 0.81) and weak bones (Kappa = 0.82).

Factors of Modeling Likelihood of High Agreement

The logistic regression model assessing the odds of high agreement created using model selection techniques was summarized in Table 5. The model includes the two exposures of diagnosis and time between appointment and baseline, while controlling for

survey type, sex, and number of visits before baseline. A diagnosis of sarcoma has 5.1 times the odds of reporting high agreement (11-12 items in agreement) referent to leukemia diagnoses (95% CI: 1.84-13.66). Reports within one month of a clinic visit were 5.44 times more likely to have high agreement than the referent group of a time lapse of 12-15 months (95% CI: 1.17-25.34). Survivors 18 years and older were 3.44 times more likely to have high agreement in comparison to caregivers of survivors under 18 for reporting late effects (95% CI: 1.56-7.37). Females were 5.85 times more likely than males to have high agreement of late effect reporting (95% CI: 1.17-29.23).

Discussion

In order to construct a comprehensive idea of the various late effects that childhood cancer survivors experience, an in-depth analysis of medical records and survey reports must be examined and compared. By incorporating additional information that may not be concretely defined in medical records, we can create a more robust summary of the late effects that may be affecting childhood cancer survivors. When looking at the agreement of late effects, there were significant differences either overall or amongst the different stratum for six of the twelve late effects. These late effects can be categorized in a few ways. The first way of looking at these is by classifying these as either general problems or conditions that can be diagnosed with a test. The conditions with concrete tests have clear diagnostic criteria and are often easily communicated. However, the general problems may be ones that are often overlooked in clinical settings. These may be seen as abstract problems, too general for acknowledgement in a survivorship program, or as not being relevant to cancer treatments when the decision is being made whether or not to discuss these at a cancer survivor appointment. As well

these may often be conditions that do not have concrete diagnostic testing or may just be seen as a new normal way of living.

When looking at overall reporting, fatigue and asthma are two conditions that do not necessarily have concrete tests to diagnose with in childhood. Due to the relative nature of fatigue and the various types of fatigue, this may be a complaint that is often overlooked by physicians, as it was reportedly more prevalent overall and in both strata (21). In each stratum, there were more than two times the amount of fatigue reports by survivors and caregivers than were reported in medical records. Because there are a multitude of reasons that survivors may be experiencing fatigue, this is an issue that should be addressed more complexly, as it has the potential to affect multiple parts of a survivor's daily functioning (22). Chronic pain is another condition found in childhood cancer survivors that is difficult to assess accurately, as it does not have clear diagnostic criteria and may vary in the degree of severity. In survivors under 18, caregivers reported less instances of chronic pain than were in the medical records (19 vs. 30, $p= 0.0781$).

Asthma, on the other hand, is a condition that proves difficult to diagnosis accurately in the pediatric population. Because of this, many symptoms of may be incorrectly reported or understood as wheezing, asthma, or reactive airway disease (23). As well, these symptoms may be present only in certain contexts and not in others, but may also require a bronchodilator or medication only on an as needed basis. For this reason, there are significant differences overall and in the 18+ population, where there were less reports of asthma by survivors than were documented in medical records. Asthma showed a low agreement of 85.25% but also had a Kappa statistic of 0.81, which is on the low end of almost perfect agreement (20).

Another category of diseases that may not be reported properly and was found in the analysis are those that may be chronic, but patients feel are handled or not of concern anymore once they have been treated or until a subsequent test has been performed. For instance, patients with hypothyroidism require medication every day. However, thyroid function levels return to normal with the proper adherence to treatment, and thus may not reported as being a current condition if they are being treated. Overall, the prevalence of hypothyroidism was higher in medical records than was reported in the surveys (20 vs. 14, $p=0.0336$). However, there was a 96.72% agreement between medical records and survey report for hypothyroidism, which showed almost perfect agreement (Kappa = 0.97) (20, 24, 25).As well, the reported prevalence of weak bones was significantly higher in medical records than in all stratum for surveys (overall, under 18, and 18+) ($p<0.05$). Unlike Louie et al., we saw a low percent agreement for weak bones, with 85.25% agreement compared to 96.4% agreement in Louie et al. (17).

Various groups of demographics had strata with higher odds of high agreement than the reference groups. For instance, consistent with previous literature, girls had 5.85 times the odds of high agreement than males (26). There was more agreement between medical records and survey report for surveys completed within one month of a clinic appointment than for surveys completed 12-15 months from last appointment (OR=5.44). As well, sarcoma survivors had 5.01 times the odds of high agreement as did survivors of leukemia. This finding could be attributed to increasing incidence of most sarcoma diagnoses as children age, with the exception of rhabdomyosarcomas being diagnosed fairly uniformly throughout childhood (1). Thus, older children may be able to more vocally express their needs and concerns to either parents or providers as they get older.

Strengths

This analysis has many strengths, including the large sample size relative to the number of childhood cancer survivors in the United States. With the initial sample size of over 600 baseline surveys, there is the ability to isolate a unique population for analysis. Thus, with a final sample size of almost 250 survivors, the data provides a robust and diverse sample from which to draw conclusions. As well, with follow-up appointments recommended each year, there is a relatively uniform amount of time between appointments for survivors. This analysis also looked at the variation in agreement stratified by time since appointment, which other studies have not done to our knowledge. This provides a framework for the messages and conversations between providers and survivors on a more routine basis than if appointment follow-up times were not recommended.

CHOA-CAYACSS is a single-institution study and allows providers and investigators easy access to medical records, which likely results in thorough documentation and higher quality data abstraction. In the survivor population, the implementation of survivor healthcare plans (SHPs) has been instrumental in providing a comprehensive medical summary with treatment history and recommendations for follow-up care (27). In addition, these summaries provide a list of current and previous test results to allow for comparison. This document allows all providers, not just cancer survivor providers, a comprehensive summary of each patient's current and past medical history in a centralized location. By utilizing the SHPs for analyzing medical records, this allows for more direct and streamlined abstraction of late effects.

Another strength of this study and the CHOA-CAYACSS population in general is the short amount of time off-therapy and subsequently, a younger population to evaluate for late effects of cancer treatments compared to previous studies (17, 18). As survivor clinic starts following patients two years after therapy has ended, almost all of the survivors in the analysis have been off-therapy for less than 15 years (98.36%). Around 42% of the survivors in our sample have been off-therapy for 2-4 years and thus continue to have consistent, routine follow-up.

Limitations

Although there are a number of strengths that make this study unique, there are limitations that must be discussed. First, the amount of information in the medical records for each patient varies greatly. This is in part due to the evolution of the use of electronic medical records in documenting the patients' visits. For instance, some patients have detailed notes to outside providers that are lengthy and contain a great amount of detail. However, others may only have very brief reports and summaries of the perceived most important things to note from the visit and discussion. Thus, not all variables were necessarily mentioned in the provider notes or any records unless they were perceived as important, previously mentioned, or actively discussed.

Second, although this was a single-institution study, not all records and test results may be in available in the electronic medical records. This could be attributed to outside referrals or the timing of the tests, as not all paper records were fully entered into electronic form upon initiation of its use. As well, there is variability in the progress notes and records for each patient over time, as the specific providers who see the patients have changed over time. This may be seen in variability of words or phrasing of the type and

severity of conditions and issues discussed during appointments. As well, as SHPs in the medical records have developed, there has been more reliance on discrete review of systems and checkboxes rather than detailed summary notes. With these changes, the type of information that is captured during a visit is slightly altered and thus may limit the uniformity of results over time.

Lastly, our sample may not be representative of the overall childhood survivor population. Our sample has a small prevalence of brain tumors, as these survivors are seen in a different type of survivor clinic at the institution. Thus, these results may not be generalizable to the entire survivor population, but rather to non-brain tumor survivors.

Clinical and Public Health Significance

These findings provide a great deal of information moving forward as we look to modify and improve current practices involving pediatric cancer survivor care and preparation for transitioning into young adult care. A previous study of the Childhood Cancer Survivor Study showed that adult survivors of childhood cancer showed deficits in knowledge of basic aspects of their diagnoses and treatments (28). However, our study shows that survivors are actually communicating and reporting fairly accurately to providers and in the CHOA-CAYACSS study. However, there is still room for improvement to address common issues.

Because of the varying degrees of many of the conditions, it is important to include this in the discussion between patients and providers. For instance, there are differences between having a history of a condition, a condition being subclinical, a condition being present but not requiring medication currently, and a condition being currently treated. For hypothyroidism and weak bones, some patients may not report the

presence of the conditions, as they believe they are controlled with medication and are no longer of importance. With this misunderstanding, there is room for improving education and tailoring education efforts more acutely. A primary goal of survivor programs is to educate survivors and healthcare providers regarding the potential late effects and promote ongoing communication between healthcare facilities (29). With increased and more tailored education programs, it is hoped that these would promote higher agreement between medical records and survey reports and a more robust reporting of late effects affecting survivors.

On the contrary, it is important for physicians to promote increased and more thorough conversations to address issues that may not have concrete diagnostic criteria. These may include things such as fatigue, chronic pain, educational, behavioral and psychosocial issues (30, 31). Thus, these should be addressed at each visit to assess for changes. Although they may not be typically perceived as conditions that the cancer survivor provider should address, these conditions have the potential to greatly impact quality of life, daily functioning, mental health, and other educational and social realms (32-39). By obtaining status updates on these types of conditions, providers can construct a more exhaustive picture of the lives of childhood cancer survivors.

This analysis shows support for a more robust understanding of long-term complications in childhood cancer survivors that requires the use of both medical records and self-report. Thus, by tailoring education and survivor visits to more closely fit the needs of survivors, we can aim to address and ameliorate as best we can each aspect of life affected by cancer treatments. However, without consultation of both types of reports, there is bound to be an underestimate of all the conditions and issues that

childhood cancer survivors face on a daily basis. It is therefore critical to consult both survivors and medical records before making any changes in medical and long-term follow-up care. By addressing these changes, we hope that we can provide suitable and comprehensive care for childhood cancer survivors as they age and transition into adulthood.

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Tables and Figures

Figure 1. Study Participation

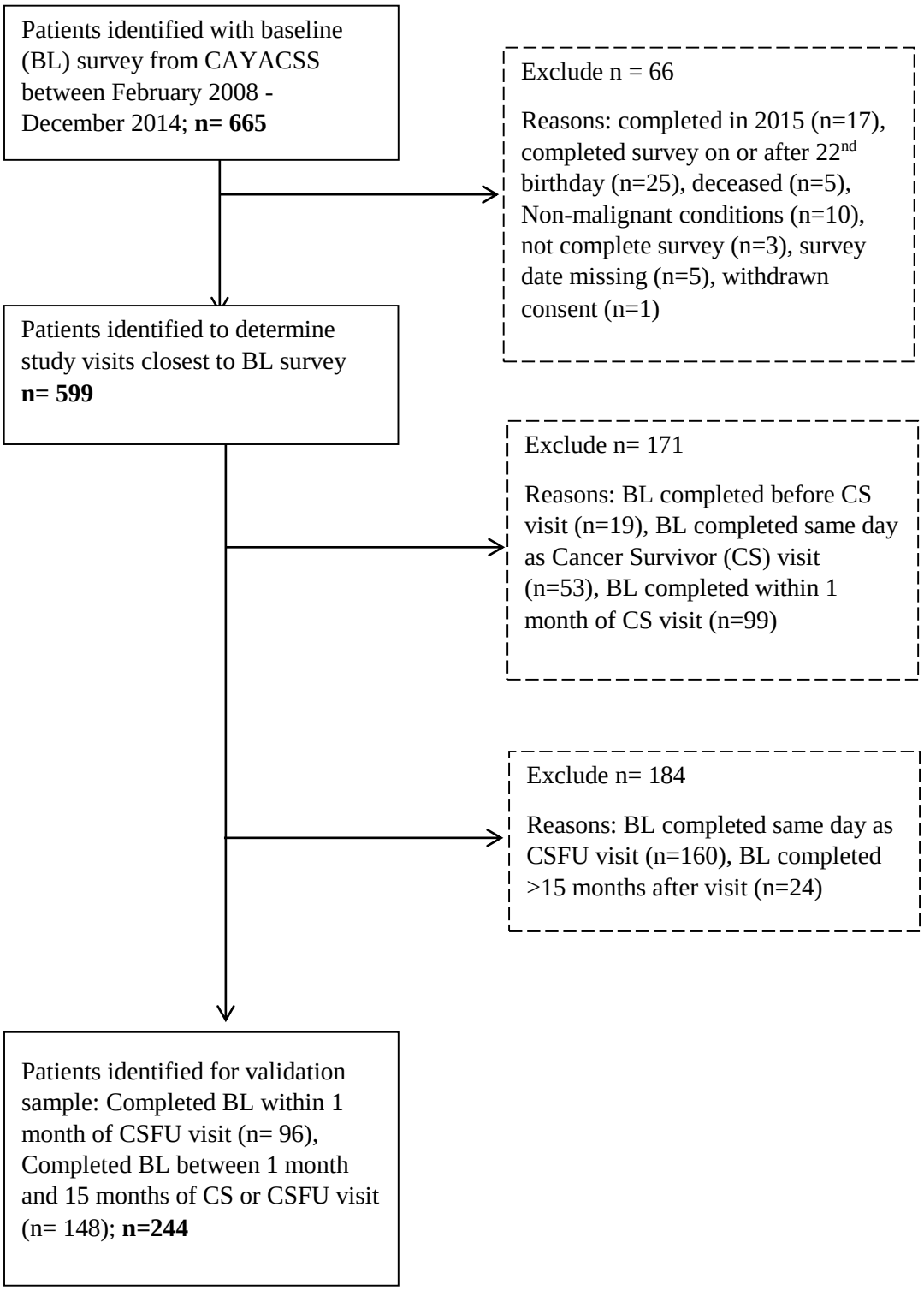


Table 1.Demographics of patients selected from CHOA-CAYACSS, n=599

	Overall (n=599) n (%)	Excluded during CS visit (n=171) n (%)	Excluded during CSFU visit (n=184) n (%)	Cases analyzed (n=244) n (%)	Chi-Square (alpha=0.05) X^2 (P-value)
Survey Type					$X^2(2) = 2.9626 (0.2273)$
Under 18 Baseline	499 (83.31)	149 (87.13)	153 (83.15)	197 (80.74)	
18+ Baseline	100 (16.69)	22 (12.87)	31 (16.95)	47 (19.26)	
Sex					$X^2(2) = 0.2717 (0.8730)$
Male	317 (52.92)	92 (53.80)	99 (53.80)	126 (51.64)	
Female	282 (47.08)	79 (46.20)	85 (46.20)	118 (48.36)	
Race/Ethnicity					$X^2(6) = 3.2509 (0.7768)$
White, Non-Hispanic	432 (72.48)	121 (70.76)	135 (74.18)	176 (72.43)	
Black, Non-Hispanic	76 (12.75)	19 (11.11)	24 (13.19)	33 (13.58)	
Hispanic	61 (10.23)	23 (13.45)	15 (8.24)	23 (9.47)	
Other [a]	27 (4.53)	8 (4.68)	8 (4.40)	11 (4.53)	
Missing	3	0	2	1	
English Spoken at Home					$X^2(2) = 4.9832 (0.0828)$
Yes	554 (92.80)	152 (88.89)	174 (95.08)	228 (93.83)	
No	43 (7.20)	19 (11.11)	9 (4.92)	15 (6.17)	
Missing	2	0	1	1	
Diagnosis					**$X^2(12) = 35.9613 (0.0003)$**
Leukemia	260 (43.41)	61 (35.67)	84 (45.65)	115 (47.13)	
Hodgkin Disease	24 (4.01)	6 (3.51)	7 (3.80)	11 (4.51)	
Non-Hodgkin Lymphoma	41 (6.84)	14 (8.19)	12 (6.52)	15 (6.15)	
Kidney Tumor	71 (11.85)	16 (9.36)	25 (13.59)	30 (12.30)	
Neuroblastoma	54 (9.02)	10 (5.85)	21 (11.41)	23 (9.43)	
Sarcoma	71 (11.85)	21 (12.28)	21 (11.41)	29 (11.89)	
Other [b]	78 (13.02)	43 (25.15)	14 (7.61)	21 (8.61)	
Age at Diagnosis					$X^2(6) = 11.1192 (0.0848)$
0-4 years	358 (59.77)	89 (52.05)	117 (63.59)	152 (62.30)	
5-9 years	142 (23.71)	42 (24.56)	46 (25.00)	54 (22.13)	
10-14 years	76 (12.69)	31 (18.13)	15 (8.15)	30 (12.30)	
15-19 years	23 (3.84)	9 (5.26)	6 (3.26)	8 (3.28)	
Age at Survey					**$X^2(8) = 58.9054 (<0.0001)$**
0-4 years	14 (2.34)	12 (7.02)	0 (0.00)	2 (0.82)	
5-9 years	153 (25.54)	66 (38.60)	26 (14.13)	61 (25.00)	
10-14 years	209 (34.89)	49 (28.65)	74 (40.22)	86 (35.25)	
15-18 years	155 (25.88)	28 (16.37)	63 (34.24)	64 (26.23)	
19-22 years	68 (11.35)	16 (9.36)	21 (11.41)	31 (12.70)	
Number of Visits Before Baseline					**$X^2(4) = 383.9682 (<0.0001)$**
0	72 (12.02)	72 (42.11)	0 (0.00)	0 (0.00)	
1	161 (26.88)	98 (57.31)	8 (4.30)	55 (22.54)	
2	140 (23.37)	1 (0.58)	72 (38.71)	69 (28.28)	
More than 2 (Range 3-9)	226 (37.73)	0 (0.00)	106 (56.99)	120 (49.18)	
Education Status of Mother (Under 18) n=499					$X^2 (12) = 12.7336 (0.3887)$
Did not finish high school	33 (6.64)	9 (6.04)	11 (7.14)	13 (6.67)	
High school or GED	77 (15.49)	30 (20.13)	19 (12.34)	28 (14.36)	
Some college	104 (20.93)	29 (19.46)	36 (23.38)	40 (20.51)	
College graduate	176 (35.41)	52 (34.90)	63 (40.91)	61 (31.28)	
Some graduate or professional school	23 (4.63)	6 (4.03)	4 (2.60)	13 (6.67)	
Graduate or professional (medical, law) school graduate	82 (16.50)	22 (14.77)	21 (13.64)	39 (20.00)	
Do not know	2 (0.40)	1 (0.67)	0 (0.00)	1 (0.51)	
Missing	2	0	0	2	
Education Status of Father (Under 18) n=499					$X^2(12) = 9.4229 (0.6665)$
Did not finish high school	42 (8.70)	13 (9.09)	17 (11.26)	12 (6.32)	
High school or GED	109 (22.57)	32 (22.38)	26 (17.22)	51 (26.84)	
Some college	92 (19.05)	30 (20.98)	28 (18.54)	35 (18.42)	
College graduate	135 (27.95)	37 (25.87)	50 (33.11)	48 (25.26)	
Some graduate or professional school	22 (4.55)	7 (4.90)	6 (3.97)	9 (4.74)	
Graduate or professional (medical, law) school graduate	77 (15.94)	23 (16.08)	22 (14.57)	32 (16.84)	
Do not know	6 (1.24)	1 (0.70)	2 (1.32)	3 (1.58)	
Missing	16	6	3	7	
Education Status of Survivor (18+) n=100					$X^2 (10) = 5.0188 (0.8899)$
Did not finish high school	10 (10.00)	1 (4.55)	1 (3.13)	8 (17.02)	
High school or GED	27 (27.00)	6 (27.27)	10 (31.25)	12 (25.53)	
Some college	60 (60.00)	14 (63.64)	20 (62.50)	26 (55.32)	
College graduate	1 (1.00)	1 (4.55)	0 (0.00)	0 (0.00)	
Some graduate or professional school	1 (1.00)	0 (0.00)	1 (3.13)	0 (0.00)	
Graduate or professional (medical, law) school graduate	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	
Do not know	1 (1.00)	0 (0.00)	0 (0.00)	1 (2.13)	

a Other races and ethnicities include Asian, Pacific Islander, and other non-specified races

b Other diagnoses for analysis sample include carcinoma (n=1), endocrine tumor (n=1), germ cell tumors (n=2), brain/central nervous system tumors (n=2), histiocytosis (n=4), liver tumors (n=5), and retinoblastomas (n=6)

Table 2. Reported Prevalence of Late Effects by Survey Report and Medical Records, stratified by survey type

	Overall Reported Prevalence (n=244)				**Under 18 Reported Prevalence (n=197)**				**18+ Reported Prevalence (n=47)**			
	Survey Report		Medical Record Report		Survey Report		Medical Record Report		Survey Report		Medical Record Report	
	N	%	N	%	N	%	N	%	N	%	N	%
Hearing	29	11.89	23	9.43	23	11.68	20	10.15	6	12.77	3	6.38
Trouble Walking **	18	7.38	15	6.15	15	7.61	8	4.06	3	6.38	7	14.89
Fatigue #	32	13.11	14	5.74	20	10.15	10	5.08	12	25.53	4	8.51
Hypothyroid*	14	5.74	20	8.20	10	5.08	15	7.61	4	8.51	5	10.64
Other Thyroid Problems	1	0.41	0	0.00	1	0.51	0	0.00	0	0.00	0	0.00
Weak Heart Muscle	2	0.82	7	2.87	2	1.02	5	2.54	0	0.00	2	4.26
Other Heart Problems	23	9.43	15	6.15	16	8.12	9	4.57	7	14.89	6	12.77
Asthma●	38	15.57	51	20.90	31	15.74	38	19.29	7	14.89	13	27.66
Chronic Pain**	25	10.25	38	15.57	19	9.64	30	15.23	6	12.77	8	17.02
Diabetes	2	0.82	2	0.82	1	0.51	2	1.02	1	2.13	0	0.00
Hormone Replacement	14	5.74	14	5.74	7	3.55	7	3.55	7	14.89	7	14.89
Weak Bones #	17	6.97	39	15.98	11	5.58	25	12.69	6	12.77	15	29.79

*Overall statistically significant, alpha = 0.05

** Under 18 statistically significant, alpha = 0.05

*** 18+ statistically significant, alpha = 0.05

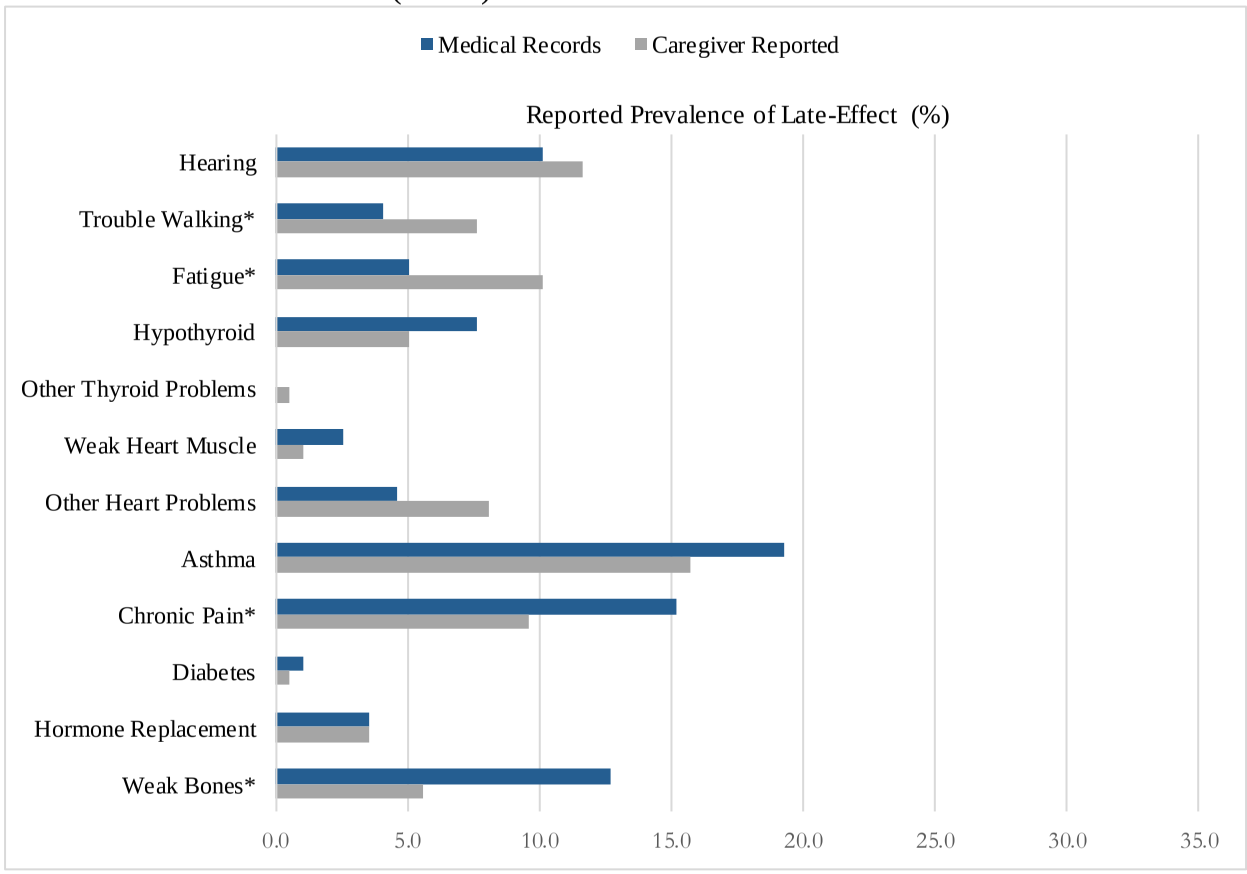
● Overall and 18+ statistically significant, alpha = 0.05

Overall and both stratum significant, alpha = 0.05

Table 3. Agreement between Survey Report and Medical Records of Late Effects, stratified by survey type

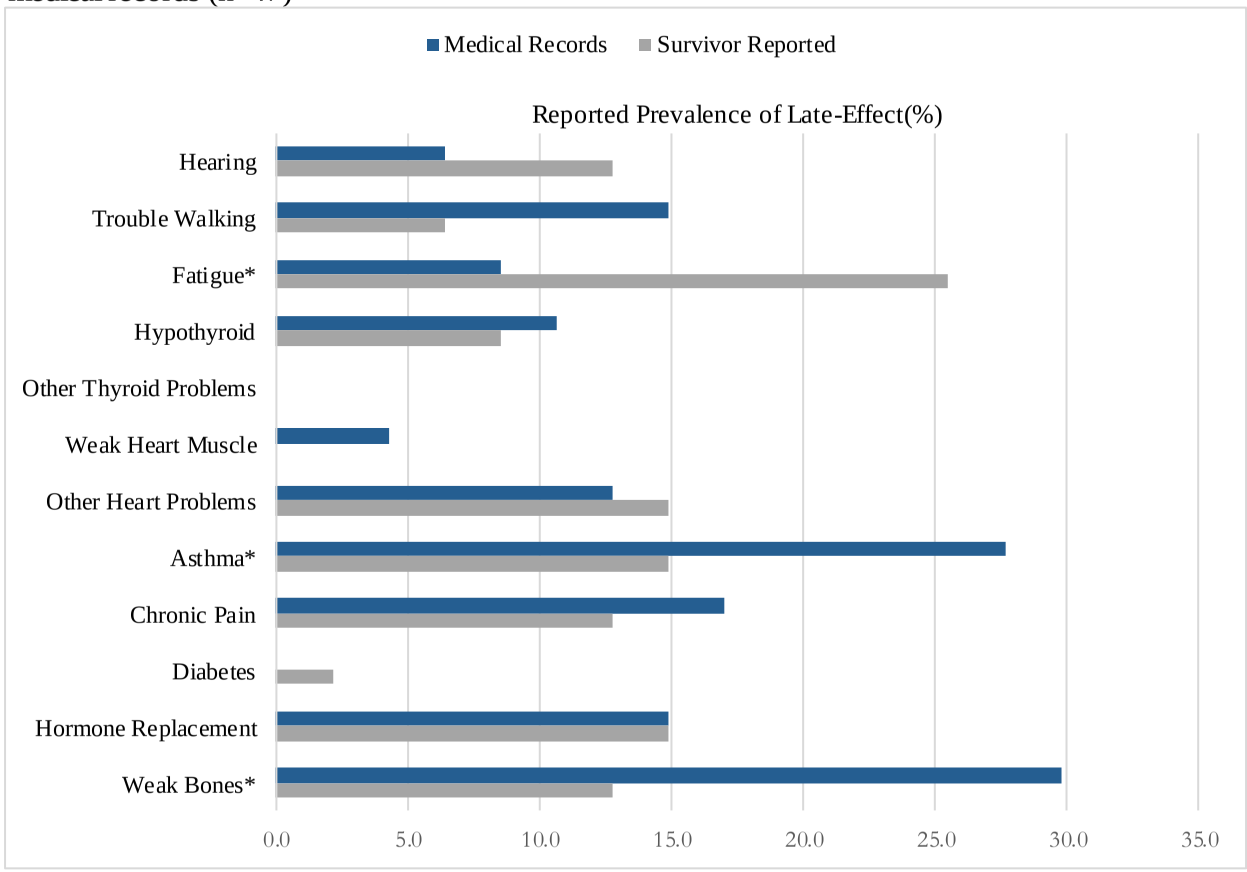
	Overall Agreement (n=244)				**Under 18 Agreement (n=197)**				**18+ Agreement (n=47)**			
	Yes	%	No	%	Yes	%	No	%	Yes	%	No	%
Hearing	230	94.26	14	5.74	186	94.42	11	5.58	44	93.62	3	6.38
Trouble Walking	231	94.67	13	5.33	190	96.45	7	3.55	41	87.23	6	12.77
Fatigue	216	88.52	28	11.48	181	91.88	16	8.12	35	74.47	12	25.53
Hypothyroid	236	96.72	8	3.28	190	96.45	7	3.55	46	97.87	1	2.13
Other Thyroid Problems	243	99.59	1	0.41	196	99.49	1	0.51	47	100.00	0	0.00
Weak Heart Muscle	237	97.13	7	2.87	192	97.46	5	2.54	45	95.74	2	4.26
Other Heart Problems	222	90.98	22	9.02	182	92.39	15	7.61	40	85.11	7	14.89
Asthma	209	85.66	35	14.34	168	85.28	29	14.72	41	87.23	6	12.77
Chronic Pain	197	80.74	47	19.26	158	80.2	39	19.80	39	82.98	8	17.02
Diabetes	242	99.18	2	0.82	196	99.49	1	0.51	46	97.87	1	2.13
Hormone Replacement	240	98.36	4	1.64	195	98.98	2	1.01	45	95.74	2	4.26
Weak Bones	208	85.25	36	14.75	175	88.83	22	11.17	33	70.21	14	29.79

Figure 2. Comparison of reported late effects by caregivers of survivors under 18 years and late effects documented in medical records (n=197)



*Statistically significant at alpha=0.05

Figure 3. Comparison of self-reported late effects by survivors over 18 and late effects documented in medical records (n=47)



*Statistically significant at alpha=0.05

Table 4. Overall agreement of self-reported long-term complications among cancer survivors compared to medical records

Long Term Complications	Number of occurrences by information in medical records/survey				Reliability		
	Y/Y[a]	N/Y[b]	Y/N[c]	N/N[d]	Agreement	%	Kappa Statistic
Hearing	19	10	4	211	230	94.26	0.94
Trouble Walking	10	8	5	221	231	94.67	0.95
Fatigue	9	23	5	207	216	88.52	0.87
Hypothyroid	13	1	7	223	236	96.72	0.97
Other Thyroid Problems	0	1	0	243	243	99.59	1.00
Weak Heart Muscle	1	1	6	236	237	97.13	0.98
Other Heart Problems	8	15	7	214	222	90.98	0.90
Asthma	27	11	24	182	209	85.66	0.81
Chronic Pain	8	17	30	189	197	80.74	0.76
Diabetes	1	1	1	241	242	99.18	1.00
Hormone Replacement	12	2	2	228	240	98.36	0.99
Weak Bones	10	7	29	198	208	85.25	0.82

[a] Y/Y, positive medical record and positive survey report

[b] N/Y, negative medical record but positive survey report

[c] Y/N, positive medical record but negative survey report

[d] N/N, negative medical record and negative survey report

Table 5. Factors associated with high agreement between medical records and survey report: a logistic regression model

Variable	OR	Confidence Intervals		Wald Chi-Square	P-Value
		95% Lower	95% Upper		
Diagnosis					
Leukemia	REF	-	-	-	-
Hodgkin Disease	1.60	0.35	7.34	0.3684	0.5439
Non-Hodgkin Lymphoma	1.43	0.34	6.08	0.2354	0.6276
Kidney Tumor	1.10	0.37	3.27	0.0270	0.8696
Neuroblastoma	2.61	0.88	7.76	2.9907	0.0837
Sarcoma	5.01	1.84	13.66	9.9237	0.0016
Other [a]	1.08	0.27	4.33	0.0128	0.9101
Time Between Appt and BL					
< 1 month	5.44	1.17	25.34	4.6630	0.0308
1-3 months	1.99	0.27	14.82	0.4540	0.5004
3-6 months	2.73	0.16	45.86	0.4887	0.4845
6-12 months	2.15	0.39	12.00	0.7660	0.3815
12-15 months	REF	-	-	-	-
Survey Type					
Under 18	REF	-	-	-	-
18 +	3.44	1.56	7.57	9.4225	0.0021
Sex					
Male	REF	-	-	-	-
Female	5.85	1.17	29.23	4.6370	0.0313
Visits Before Baseline					
1	REF	-	-	-	-
2	0.59	0.20	1.78	0.8708	0.3507
3 or more	0.66	0.25	1.78	0.6742	0.4116

[a] Other malignancies include carcinoma (n=1), endocrine tumor (n=1), germ cell tumors (n=2), brain/central nervous system tumors (n=2), histiocytosis (n=4), liver tumors (n=5), and retinoblastomas (n=6)