

ABSTRACT

Longitudinal Assessment of Patient-Reported Cumulative Symptom Burden as an Indicator of Chronic Health Conditions in Adult Survivors of Childhood Cancer: A Joint Report of the St. Jude Lifetime Cohort (SJLIFE) and the Childhood Cancer Survivor Study (CCSS)

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Background: Adult survivors of childhood cancer experience a high cumulative burden of therapy-related chronic health conditions (CHCs). However, longitudinal evaluation of patient-reported symptoms has not been examined as an indicator of CHCs in this population.

Methods: 735 long-term adult survivors of childhood cancer completed three symptom surveys through participation in both SJLIFE and CCSS across 25 years (1992-2016). Surveys included 10 symptom domains: sensory, cardiac, pulmonary, musculoskeletal, memory, pain, fatigue, nausea, anxiety and depression. Domains were classified as present vs. absent at each time point and summated with possible scores ranging from 0 to 30. Cardiac, pulmonary and endocrine CHCs were clinically determined after the last survey and graded using modified CTCAE criteria. Poisson regression identified associations of cumulative symptom burden (dichotomized as high [top quartile of the symptom burden scores] vs. low [bottom three quartiles]) with each organ system-specific CHC (grades 2-4 vs. 0-1) and severe/life-threatening CHCs (any grades 3-4 vs. 0-2), adjusting for age, sex, race and education.

Results: Across the three symptom surveys, survivors' mean ages were 27, 36 and 40 years; mean years from diagnosis was 31 years at the final clinical assessment. Survivors were mostly female (51%), Caucasian (90%) and treated for leukemia (46%). Survivors with high cumulative symptom burden had a 30% increased risk of hypertension/dyslipidemia (RR 1.3, 95% CI 1.1 1.6) and endocrine dysfunction (RR 1.3, 95% CI 1.0 1.7), and a 40% increased risk of respiratory disorders (RR 1.4, 95% CI 1.2 1.8) compared to survivors with low symptom burden. High cumulative symptom burden was associated with a 50% increased risk of having severe/life-threatening CHCs (RR 1.5, 95% CI 1.2 1.9) compared to those with low symptom burden.

Conclusions: Routine symptom screening may help identify adult survivors of childhood cancer who are at concurrent and/or future risk of hypertension/dyslipidemia, endocrine and respiratory disorders.

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