

Psychosocial Functioning in a Large Scale Cohort of Childhood Cancer Survivors: A Report From the Childhood Cancer Survivor Study

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BACKGROUND: Over the last forty years improvements in the treatment for childhood cancers have resulted in a dramatic increase in the likelihood of survival. With childhood cancer becoming increasingly curable, there has been more attention to the long-term effects on these children as they mature into adulthood. In addition to medical sequelae there have been concerns that survivors may be at risk for problems with social functioning, learning disabilities, discrimination in employment and insurance, as well as depression, anxiety and post-traumatic stress. At the same time the possibility of positive effects of cancer on personal growth and development have also been posited. The Childhood Cancer Survivor Study (CCSS) was developed to address these issues in a large cohort of survivors. **METHODS:** 25 clinical centers identified 20,276 eligible individuals who survived five years or more following diagnosis of a childhood cancer. Of these 14,054 (69%) subjects ages 5-48 years enrolled. Cancer treatment information was abstracted at the treating center, and current medical, social and psychological functioning was assessed using a mailed survey or telephone interview with survivors or parents of survivors under 18. Similar information was obtained from 3,585 of the survivors' siblings, and both groups are followed with periodic surveys. **RESULTS:** Analyses on various aspects of survivors functioning have been completed. 44% of survivors reported at least one adversely affected health status domain. Overall, when compared to siblings, survivors were significantly more likely to report adverse general (relative risk (RR) = 2.5, $p < 0.001$) and mental health (RR=1.8, $p < 0.001$), as well as more activity limitations (RR=2.7, $p < 0.001$) and functional impairment (RR=5.2, $p < 0.001$). Data on self-reported mental health domains demonstrated that survivors were significantly more likely to be at higher risk for depression (RR=1.7), somatization (RR=2.2) and anxiety (RR=1.9). Detailed analyses of diagnosis-specific subgroups including childhood brain tumors, leukemia and lymphoma found significantly higher global distress and depression. Psychological distress in this group has been associated with poor physical functioning indicating that some sub-groups of patients may be at risk for these problems. Survivors have been shown to be more likely to require special education services, particularly if the CNS was directly treated. High school graduation rates for these survivors were generally lower than for siblings, although the provision of remediation services was effective in increasing graduation rates. Survivors reported lower marriage rates compared to siblings, which is most striking among survivors of CNS tumors. Similar results were found in a study of CCSS subjects treated for bone cancer with leg amputation. This group of patients did not report more psychological distress, but did report deficits in education, employment and health insurance. Analyses in progress are examining several additional aspects of survivors' psychosocial functioning including, pain outcomes, suicide, and preventative health behaviors. **CONCLUSIONS:** The CCSS is a unique resource for the study of psychological late effects of childhood cancer and treatment. Studies to date show survivors as a group are demonstrating varying degrees of psychological distress, and report problems with adaptation to school and work. Analysis of this dataset has identified risk factors for poor long-term adaptation which can now make possible targeted educational and therapeutic interventions.

Keyword(s): childhood cancer, survivors, late-effects, psychological distress, quality-of-life