Pain Prevalence among Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS)

Lu Q, Myers CD, Owen J, Zebrack BJ, Zevon MA, Mertens A, Robison LL, and Zeltzer LK

1. Pediatric Pain Program, University of California at Los Angeles.
2. University of Southern California School of Social Work
3. Roswell-Park Cancer Institute
4. University of Minnesota

While increased cancer survival has focused attention on the detection of late effects, few studies have investigated pain in long-term survivors of childhood cancer. The prevalence of questionnaire-based self-reports of pain was assessed in 14,024 childhood cancer survivors (five years post-diagnosis and alive at study entry) and 3,701 siblings participating in the CCSS. Survivors’ age at diagnosis was a mean of 8.3 years (range 0-21) and at study entry was a mean of 23.2 years (range 5-48) (siblings: 25.9 years, range 1-56). In univariate analyses, survivors were more likely than siblings to report pain/abnormal sensation (11.6% vs. 5.2%), frequent headache (19.4% vs. 13.6%), use of muscle relaxants (4.5% vs. 2.9%), and analgesics (16% vs. 10.9%), all p<0.001. The two diagnoses reporting the most pain for each category were: headaches: CNS tumors (22.2%) and Hodgkin's disease (20.9%); pain/abnormal sensation: bone cancer (19.5%) and soft tissue sarcoma (13.2%); analgesics: bone cancer (22.6%) and soft tissue sarcoma (19.1%); and muscle relaxants: bone cancer (7.5%), soft tissue sarcoma (5.7%).

Multivariate analyses identified the following risk factors for experiencing any of the pain symptoms or use of analgesics or muscle relaxants among survivors: being female (RR= 1.77, 95% CI 1.64 -1.91), annual income <$19,000 (RR= 1.51, 95% CI 1.37 - 1.66), age >18 years at study entry (RR=1.34, 95% CI 1.22-1.47), and diagnoses of bone cancer (vs. leukemia) (RR= 1.32, 95% CI 1.14-1.53), all p<0.001; Hispanics had higher risk (RR=1.20, 95% CI 1.003-1.44) and Asians lower risk (RR= 0.53, 95% CI, 0.34-0.81) than Caucasians (p< .05). Subsequent research will examine the diagnosis- and treatment-related pathways to pain in childhood cancer survivors. (Supported by grant CA 55727)