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

Lu Q¹, Myers CD¹, Owen J¹, Zebrack BJ², Zevon MA³, Mertens A⁴, Robison LL⁴, and Zeltzer LK¹

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 (19.1%); 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)