

Pain Prevalence and Retrospective Incidence in Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study

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PURPOSE: Recent CCSS data suggests that childhood cancer survivors experience pain as a late-effect of treatment, yet types and trajectories of pain experiences are poorly understood in this population. In this study, we sought to characterize the prevalence of pain in childhood cancer survivors and to describe incidence rates with respect to time of diagnosis and treatment.

METHODS: Participants included 14,024 childhood cancer survivors who were five or more years post-diagnosis and completed baseline questionnaires as part of the CCSS survivor cohort and 3,701 siblings who served as controls. Participants were asked to self-report whether they had ever been diagnosed with any of three types of pain (pain/abnormal sensation, frequent headaches, or migraine headaches), the age at which each pain type had been diagnosed, and use of medications for pain. Prevalence rates for each of the three types of pain conditions were compared between survivors and siblings. Additionally, retrospective incidence was calculated from participants' estimated date of diagnosis of the pain condition.

RESULTS: Prevalence of pain or abnormal sensation, frequent headaches or migraines, and use of pain medications was significantly higher among survivors than siblings. 11.6% of childhood cancer survivors reported pain/abnormal sensations, 23.4% reported frequent headaches or migraines, 17.1% reported use of pain medications. Survivors were at significantly greater risk for developing each of the types of pain experiences at all time points subsequent to diagnosis and were at greater risk for pain/abnormal sensation and frequent headache even in the time period prior to their cancer diagnosis.

CONCLUSION: These results suggest that pain is an important late effect of pediatric cancer treatment, although differences between survivors and siblings may become attenuated with increasing time from the end of treatment. Additionally, survivors may be at greater risk of experiencing recurrent or chronic pain conditions, although this finding must be confirmed by prospective studies. It would appear prudent to include assessment of painful conditions as part of caring for the health and well-being of individuals with a history of childhood cancer..

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