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Social Adjustment in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS)

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PURPOSE: With the growing number of childhood cancer survivors in the United States, it is important to understand their unique social needs, particularly the impact on social development during childhood and the transition into adolescence and young adulthood.

METHODS: The CCSS is a resource designed to investigate long-term effects among 5-year survivors of childhood and adolescent cancer diagnosed between 1970-86. Eligible diagnoses included leukemia, lymphoma, neuroblastoma, CNS malignancy, bone or soft tissue sarcoma and Wilms tumor. A random sample of siblings of the cancer survivors were also invited to participate. This analysis utilized six parent-reported social adjustment domains of a 32 item survey modified from the Child Behavior Checklist. Principle components analysis was used to construct the scales, and the sibling score distribution was used to classify dichotomous outcomes in each domain.

RESULTS: Those eligible included 3,451 5-year childhood cancer survivors and 813 siblings all of whom were <18 yrs old at data collection. Multiple variable analysis was performed adjusting for sex, race/ethnicity, age at study, age at diagnosis, current use of psychotropic medications, and head, limb or chest disfigurement. Within these domains, parents were more likely to report survivors to have depression (RR=1.4,95% CI:1.1-1.9), behavior problems (RR=1.4,95% CI:1.0-1.8), attention problems (RR=1.3,95% CI:1.0-1.7), interpersonal problems (RR=1.8,95% CI:1.3-2.3), and poor social competence (RR=1.7,95% CI:1.1-2.6) compared to siblings; no difference was seen for social deviance (RR=1.1,95% CI:0.8-1.4). Parents of leukemia and CNS tumor survivors were most likely to report difficulties in the same five domains when compared to siblings. Compared to children who received neither methotrexate or cranial radiation (CRT), children who received CRT were more likely to have reports of depression (RR=1.5,95% CI:1.1-2.0), attention problems (RR=1.8,95% CI:1.4-2.4) and poor social competence (RR=2.6,95% CI:1.9-3.6). Children who received both methotrexate and CRT were also reported to have difficulties in the same three domains.

CONCLUSION: Overall, children who survive childhood cancer have more social adjustment problems than the sibling comparison group. Children diagnosed with leukemia

or CNS tumors, and those who received cranial radiation are at the greatest risk for social adjustment problems and should be the focus of future interventions.

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Conclusion: Overall, children who survive childhood cancer have more social adjustment problems than the sibling comparison group. Children diagnosed with leukemia or CNS tumors, and those who received cranial radiation are at the greatest risk for social adjustment problems and should be the focus of future interventions.