

WHAT DO CHILDHOOD CANCER SURVIVORS KNOW ABOUT THEIR PAST DIAGNOSIS AND TREATMENT?: A REPORT FROM THE CHILDHOOD CANCER SURVIVOR STUDY. N. Kadan-Lottick, L. Robison, J. Gurney, J. Neglia, Y. Yasui, R. Hayashi, M. Hudson, M. Greenberg, A. Mertens. University of Minnesota, Minneapolis, 55455; Fred Hutchinson Cancer Research Center, Seattle, 98109; St. Louis Children's Hospital, St. Louis, 63110; St. Jude Children's Research Hospital, Memphis, 38105; Hospital for Sick Children, Toronto, M5G1X8.

Adult survivors of childhood cancer are at risk for adverse late effects, but may have limited access to information pertaining to their diagnosis and treatment. We conducted a cross-sectional survey of 635 consecutive individuals (5%) drawn from the 11,984 participants ≥ 18 years old in the Childhood Cancer Survivor Study (a multi-institutional cohort of survivors diagnosed with childhood cancer between 1970-1986 who had survived 5 years from diagnosis). The subjects underwent a 3-5 minute telephone interview regarding their diagnosis and treatment. Responses were then compared to medical record data. The distribution of diagnoses among participants was similar to that of the entire cohort: leukemia (33%), central nervous system (CNS) tumor (14%), Hodgkin's disease (13%), non-Hodgkin's lymphoma (7%), neuroblastoma (7%), Wilms tumor (8%), soft tissue sarcoma (9%), and bone cancer (9%). Overall, 72% accurately and specifically reported their diagnosis and 20% were accurate, but non-specific. Individuals with central nervous system (CNS) tumor (OR=5.1; 95% CI= 2.6-9.9) and neuroblastoma (OR=4.2; 95% CI=1.8-9.6) were more likely to not know their cancer diagnosis; inaccurate response rates were 24% and 21%, respectively. Participants reported their history (yes/no) of chemotherapy, radiation therapy, and splenectomy with accuracy rates of 94%, 89%, and 93%, respectively. Among those who received anthracyclines, only 30% recalled Daunorubicin therapy and 52% recalled Doxorubicin therapy, even after prompting with the drugs' names. Among those who received radiotherapy, 70% could recall the site. History of receiving a written medical summary, attending a long-term follow up clinic and anxiety about late effects were not associated with greater knowledge. Important knowledge deficits exist among adult survivors of childhood cancer regarding basic aspects of their diagnosis and treatment. Such deficits could impair survivors' ability to seek and receive appropriate long-term follow-up care.