

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.

**Purpose:** 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. Such knowledge is necessary to be motivated to pursue medical follow-up and to report essential history to health care providers. We assessed knowledge of adult survivors of childhood cancer regarding their primary cancer diagnosis and associated therapies.

**Methods:** 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 long-term survivors diagnosed with childhood cancer between 1970 –1986). The subjects underwent a 3-5 minute telephone interview regarding their diagnosis and treatment. Responses were then compared to medical record data. **Results:** Overall, 72% accurately and specifically reported their diagnosis and 20% were accurate, but non-specific. Individuals with central nervous system (CNS) cancer (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. The following displays individuals' knowledge of previous treatment:

	Chemotherapy History			Radiation History (yes/no)	Splenectomy History (yes/no)
	Overall (yes/no)	Daunorubicin (yes/no)	Doxorubicin (yes/no)		
Accuracy	94%	85%	77%	89%	93%
Sensitivity	99%	8%	33%	99%	67%
Specificity	90%	99%	99%	90%	99%
Pos Predictive Value	97%	75%	94%	96%	91%
Neg Predictive Value	96%	88%	77%	99%	96%

**Conclusions:** 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.