Title: LONGITUDINAL CHANGES IN HEALTH CARE UTILIZATION BY ADULT SURVIVORS OF CHILDHOOD CANCER IN THE CHILDHOOD CANCER SURVIVOR STUDY (CCSS)

Authors: Jacqueline Casillas MD, MSHS1, Qi Liu MS2, Melissa Hudson MD3, Mark L Greenberg MB, ChB4, Mark W Yeazel MD, MPH5, Kirsten Ness PT, PhD5, Leslie L Robison PhD3, Gregory T Armstrong MD, MSCE3, Wendy Leisenring ScD3, Yutaka Yasui PhD2, Kevin C Oeffinger MD, MSCE3, and Paul C Nathan MD, MSc4

Author Affiliations: 1Department of Pediatrics, University of California, Los Angeles, Los Angeles, California, USA; 2Department of Public Health Sciences, University of Alberta, Edmonton, Alberta, Canada; 3Departments of Epidemiology and Cancer Control and Oncology, St. Jude Children’s Research Hospital, Memphis, Tennessee, USA; 4Department of Paediatrics, The Hospital for Sick Children, Toronto, Ontario, Canada; 5Department of Family Medicine and Community Health, University of Minnesota Medical School, Minneapolis, Minnesota, USA; 6Departments of Pediatrics and Medicine, Memorial Sloan-Kettering Cancer Center of Pediatrics, New York, New York, USA.

Purpose: We assessed longitudinal changes in health care utilization in adult survivors of childhood cancer participating in the CCSS.

Methods: Utilization at baseline and most recent follow-up was classified into one of three mutually exclusive hierarchical categories: no health care, general medical care, or survivor-focused care. Relative risk (RR) and 95% confidence intervals (CI) were calculated for predictors of reduction in care over time from survivor-focused to general or no care. Multivariable models, adjusted for key treatment exposures, were created to assess risk factors for reductions in level of care over time.

Results: Among 8591 eligible survivors, mean age at last follow-up was 35.1 years (SD=7.8) with a mean of 11.6 years (SD=2.2) since baseline. Of 3993 (46%) survivors who reported survivor-focused care at baseline, 2383 (59.7%) reported a lower level of care at follow-up. Among 4598 (54%) not receiving survivor-focused care at baseline, 915 (20%) reported survivor-focused care at follow-up. Baseline predictors of a decreased level of care were no health insurance (RR=1.5, 95% CI 1.2-1.9), male sex (RR=1.4, 95% CI 1.2-1.6), being 10-19 years from diagnosis compared with 20+ years (RR=1.4, 95% CI 1.1-1.7). Factors associated with a maintenance in survivor-focused care were Canadian residency compared to U.S. residency with insurance (RR=0.7, 95% CI 0.6-0.9), unemployment (RR=0.8, 95% CI 0.7-0.9), physical limitations (RR=0.7, 95% CI 0.6-0.9), cancer-related pain (RR=0.7, 95% CI 0.5-0.8), poor emotional health (RR=0.7, 95% CI 0.5-0.9), having mild-moderate (RR=0.5, 95% CI 0.4-0.6) or severe-disabling chronic health condition (RR=0.6, 95% CI 0.5-0.7).

Conclusions: Less than a third of adult survivors of childhood cancer report survivor-focused care. Rates decrease over time. Targeted interventions to maximize survivor-focused care should be tested so risk-reducing opportunities are not lost.