

Title: An exploration of Childhood Cancer Survivor Study participants' knowledge and confidence about health insurance plans and policies

Cayley Bliss, BA¹, Anne C. Kirchhoff, PhD, MPH², Giselle K. Perez, PhD¹, Karen A. Kuhlthau PhD,¹ Aaron McDonald, PhD³, Karen Donelan, ScD¹, Allyson Foor, BA¹, Karely Mann MS², Austin Waters, MSPH², Wendy Leisenring, ScD⁴, Gregory Armstrong MD³, Elyse R. Park, PhD, MPH¹

¹Massachusetts General Hospital, Boston, MA

²Huntsman Cancer Institute, Salt Lake City, UT

³St. Jude Children's Research Hospital, Memphis, TN

⁴Fred Hutchinson Cancer Research Center, Seattle, WA

Background: Childhood cancer survivors are vulnerable to health insurance-related financial burden. Adequate health insurance literacy (HIL) and knowledge of Affordable Care Act (ACA) policies and other federal legislation could facilitate survivors' health insurance use and financial protection.

Methods: Using baseline data from a randomized pilot health insurance navigation trial, we assessed HIL (16-items assessing knowledge/confidence with health insurance terms and activities; range= 16 to 64; lower scores= higher HIL), familiarity with health insurance legislation/policies (very/somewhat vs. not at all), and knowledge of ACA protections (8-items; yes=endorsed knowledge) among insured survivors from the Childhood Cancer Survivor Study.

Results: From August 2020-May 2021, 82 participants enrolled (53.7% female; 91.0% white, 4.9% Hispanic, and 6.4% black; 52.4% <40 years); 73.2% were insurance policy holders and 75.6% had employer-sponsored insurance. Average HIL scores were 28.5 (SD=9.0). For knowledge of health insurance terms, >60% were very confident about premiums, deductibles, co-payments, and in-network providers; only 30.5% were confident about co-insurance and 49.4% about out-of-pocket maximums. Confidence in health insurance use was low; 36.6% knowing what services their plan covered, 25.6% knowing how to calculate in-network costs, and 17.1% knowing how to estimate out-of-network costs or file an appeal. Familiarity with legislation included: FMLA (63.0%), ACA (60.1%), and ADA (51.2%). Endorsed knowledge about ACA protections included: dependent coverage until 26 years (89.0%), prohibitions on pre-existing condition coverage denial (73.2%), and preventive care coverage requirements (49.4%); however, only 24.4% knew about no annual lifetime limits, and 43.9% knew how to file an appeal.

Conclusion: Most childhood survivors endorsed understanding many health insurance terms and ACA provisions. However, survivors have low confidence navigating protections, such as filing appeals or cost-driving aspects of their coverage, which could protect them financially. Findings support the need for a psychoeducational health insurance program to help survivors apply knowledge to optimize insurance use.