Title: Feasibility of a health insurance navigation program for childhood cancer survivors: an intervention trial in the Childhood Cancer Survivor Study

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

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: With ongoing healthcare needs, childhood survivors are vulnerable to being underinsured and to experiencing health insurance-related financial burden. Low health insurance literacy reduces survivors’ ability to utilize health insurance. We describe feasibility results of a pilot trial to develop a virtually delivered health insurance navigation intervention.

Methods: Using an iterative intervention development design, we developed a 4-session health insurance intervention, delivered synchronously by a navigator via Zoom, using 1) in-depth interviews with 28 survivors and experts and 2) an open pilot with 8 survivors. Eligible participants were insured survivors from the Childhood Cancer Survivor Study (CCSS) with access to a wireless device. We assessed feasibility by the percent of eligible participants who enrolled, sessions completed, and follow-up surveys completed.

Results: From August 2020 to May 2021, 82 CCSS participants enrolled; 53.7% female; 82% white, 7% Hispanic, and 7% black; 52.4% <40 years of age; 72.0% college educated; 38.5% from a non-expansion state; 75.6% had employer-sponsored insurance and 17.1% had public coverage; 72.1% were the policy holder for their insurance. Baseline health insurance literacy scores were low (mean 28.5, sd=9.0; range 16-60; higher scores=poor literacy). 39.0% were not familiar with the Affordable Care Act (ACA), and many lacked knowledge of relevant ACA provisions. Over half lacked awareness of essential benefits coverage and did not know they had the ability to file appeals for denied coverage. 98% of screened participants were eligible; 39.7% of participants approached consented; 82% completed all 4 sessions; 92.6% (75/81 in survey window (10/21)) completed the 5-month follow-up survey.

Conclusion: Findings affirm gaps in health insurance literacy among a national sample of insured survivors. The significance and need for this intervention were underscored by low health insurance literacy, even among educated long-term survivors. Results strongly support the feasibility of a virtual health insurance navigation program targeted for childhood survivors.