

Understanding and Improving Health Insurance Coverages Experiences of CCS (Childhood Cancer Survivors)

Working Group(s): Cancer Control and Intervention

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Overview: This concept proposal is for Dr. Elyse Park's ongoing American Cancer Society (ACS) grant to pilot test a health insurance literacy program for survivors from the Childhood Cancer Survivor Study (CCSS). This health insurance literacy program was informed by her Livestrong-funded insurance survey of CCSS survivors and siblings conducted in 2010-2011. The pilot trial (Aim 2) has almost completed data collection (anticipated completion date December 2021). Analyses will begin shortly once data collection is finalized and the concept proposal is approved.

Per input from the CCSS Publications Committee, the ACS grant will be reviewed in place of a CCSS concept proposal.

Draft table shells for the Aim 2 RCT analyses and relevant CCSS variables are listed at the end of the concept proposal.

A. SPECIFIC AIMS

Childhood cancer survivors develop acute and chronic health problems at over 3-times the rate of their siblings.¹ These survivors often face continued health care challenges and require ongoing care to monitor and treat long-term effects of their cancer and treatment.² Given their ongoing health care needs, obtaining and utilizing health insurance coverage is vital to ensure adherence to needed survivorship care. Unfortunately, childhood cancer survivors have reported higher rates of uninsurance, unmet health care needs, and burdensome costs.³⁻⁹ Many survivors may find themselves underinsured, either by having unmet health care needs due to cost or having high out-of-pocket (OOP) health care costs.¹⁰⁻¹² Insured survivors may still lack access to desired specialist providers, tests, and screenings due to cost or other insurance restrictions. High-deductible health plans are being increasingly offered by employers and to enrollees in health insurance exchanges. These plans pose a risk of unmet health care need and financial burden for enrollees with chronic conditions such as childhood cancer survivors.^{1,13-15}

Health care reform under the Patient Protection and Affordable Care Act (ACA) offers considerable opportunities for childhood cancer survivors to obtain coverage and improve access to needed care.^{16,17} However, in the general population, many people have low understanding of available insurance benefits and resources, and have limited health insurance literacy (i.e. perceived knowledge, ability, and confidence to make informed decisions about choosing and using health insurance).¹⁸ Misperceptions about which services require out-of-pocket costs may lead some enrollees to avoid services that are in fact exempt from cost-sharing.¹⁹ Similarly, findings from our Livestrong-funded 2011-2012 health insurance survey (PI: Park) demonstrated that many childhood cancer survivors lack of awareness about the ACA and had concerns about rising costs and threats to healthcare quality.^{4,20,21} Additionally, our research confirmed that childhood survivors, compared to siblings, were at risk for being underinsured. Thus, even with coverage protections from the ACA, barriers to obtaining coverage (e.g., in states without health insurance exchanges) and accessing needed care may remain for childhood survivors. Understanding and navigating insurance benefits is crucial for cancer survivors to obtain the health care they need. In this new post-reform landscape, the degree to which coverage and costs have changed for childhood cancer survivors is still largely unknown.

In response to the ACS RFA: *The Role of Health Policy and Health Insurance in Improving Access to and Performance of Cancer Prevention, Early Detection, and Treatment Services*, which calls for research evaluating the impact of changes in the healthcare system intended to improve access to care, we propose to conduct a mixed methods study among Childhood Cancer Survivor Study (CCSS) participants to develop a health insurance navigation program (HINP), conduct a randomized pilot trial comparing the HINP to enhanced usual care (n=80), and refine the HINP for future use. *The research is strongly aligned with the ACS's "4 A's" (availability, affordability, adequacy, and administrative simplification of coverage).*

Thus, our proposed aims are as follows:

Aim 1. To develop a psychoeducational health insurance navigation program (HINP).

Aim 1a: To qualitatively assess 4 survivor focus groups participants' report of 1) satisfaction with their current insurance coverage, 2) barriers and facilitators to obtaining needed coverage, 3) types of services where coverage and affordability are problematic, and 4) aspects of coverage not well understood.

Aim 1b: To qualitatively assess 3 advisory board experts' feedback on 1) survivor eligibility for the HINP, 2) HINP content, 3) navigator selection, 4) HINP structure and dose, and 5) resources.

Aim 1c: To pilot the intervention with childhood survivors (n=10).

Aim 2. To conduct a videoconferencing based pilot randomized trial of the HINP (n=80 participants)

Aim 2a: To assess the feasibility (number of eligibles enrolled and sessions completed) and acceptability (satisfaction, perceived support) of survivors undergoing the HINP.

Aim 2b: At 3-month post-program follow-up, to assess the efficacy of the HINP to assist survivors with accessing and utilizing coverage and managing costs. Primary outcomes are 1) health insurance literacy and 2) financial distress related to medical costs.

Hypotheses: The HINP, compared to enhanced usual care, will improve childhood survivors' health insurance literacy and decrease financial distress.

Aim 3. To refine the HINP program for future use (n=40 intervention participants).

Aim 3a: To explore HINP intervention arm participants' 1) satisfaction with the intervention, 2) recommendations for modifications on delivery modality, and 3) recommendations for intervention topics and content modifications.