



# Empowering childhood cancer survivors through integrated, individualized health insurance education

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**Abstract:** Financial toxicity is a well-documented side effect of cancer treatment, and can be a lifelong burden for childhood cancer survivors (CCS). CCS have difficulty maintaining adequate health insurance and this results in decreased healthcare visits, reduced survivor-focused healthcare, and missed outpatient clinic appointments. For CCS transitioning into adult care, understanding health insurance—how to get it, keep it, and use it—is a key aspect of combatting financial toxicity and of maintaining ongoing survivorship care. Thus, there is a clear role for longitudinal education on health insurance for CCS. In the Childhood Cancer Survivor Program at the University of Minnesota, health insurance education and counseling delivered by social workers has been incorporated as a regular part of routine survivorship care visits. In this commentary we provide a rationale for why health insurance education is crucial for CCS, describe our existing program for delivering this education, and make recommendations for future programs and directions in the current healthcare landscape. We believe our experience incorporating insurance education into clinical care is unique, and in sharing it, we hope to raise awareness of the need for health insurance education as part of cancer survivorship care and also to springboard future research and collaborative efforts in this realm.

**Keywords:** Childhood cancer survivors (CCS); health insurance education; cancer survivorship; transition care; financial toxicity

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## Introduction

Health insurance in the United States of America is complicated and can be confusing to navigate. Yet, it's a vital component for access to medical care in this country. For pediatric cancer survivors transitioning into

adulthood, understanding health insurance—how to get it, keep it, and use it—is a key element of survivorship care and independently managing health needs. This issue is particularly relevant to this group because financial toxicity, defined as the negative financial impact of cancer, is a well-documented side effect of cancer treatment (1), and is an

important, though poorly addressed, long-term reality for childhood cancer survivors (CCS) (2). An essential component in the maturation of a CCS into adulthood includes financial independence, which includes transition from principally receiving parental financial support to becoming an independent earner. An additional aspect of this transition is assuming responsibility for one's own medical decision making, including the management of associated expenses and the medical insurance coverage necessary to do so. An inability to efficiently make this adjustment may result in early adulthood financial toxicity and threatened long-term financial stability. Recognizing that CCS may require more frequent medical care into adulthood, it is essential to empower patients with a practical understanding of health insurance navigation so they can maintain access to affordable, high-quality medical care. The Childhood Cancer Survivor Program (CCSP) at the University of Minnesota (UMN) uses a model of individualized, age-appropriate health insurance education and counseling to achieve this goal.

#### ***Rationale for educating CCS on health insurance***

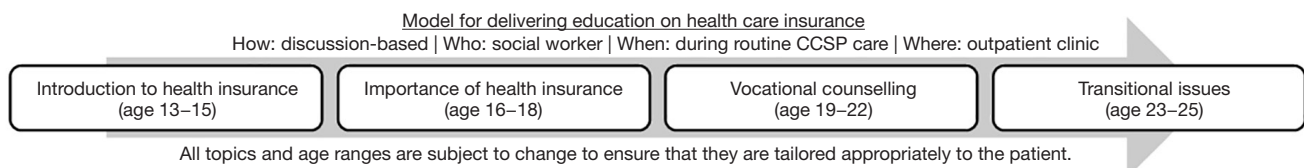
A childhood cancer survivor is defined as an individual who has received and completed treatment for cancer by a childhood cancer provider and diagnosed before the age of 25 years. CCS have difficulty obtaining and maintaining adequate health insurance when compared to the general population (3) and matched sibling controls (4,5). When they do have coverage, it tends to be lower quality with higher out-of-pocket costs (6). This results in decreased healthcare visits (7-9), reduced survivor-focused healthcare (10,11), and missed outpatient clinic appointments (12). Consequently, CCS sometimes experience delays in necessary medical care and are often unable to afford it (13). A lack of health insurance for CCS is also associated with adverse outcomes in mental health (5), increased psychological distress, and decreased health-related quality of life (14).

Insurance coverage may also influence willingness to transition from pediatric to adult care when the time is appropriate. In a 2012 cross-sectional survey study of 103 young adult CCS, 97% (100/103) of respondents indicated that insurance acceptability was either "Important" or "Very Important" in their decision to transition from a pediatric- to an adult-centered survivorship program (15). Health insurance and access to medical care were also noted as key components in a patient's ability to successfully

transition from pediatric to adult care in the validation of the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) tool (16). Not only does the presence of health insurance matter, but the details of coverage are important, too. CCS prioritize health insurance coverage for primary care, preventative services, and access to necessary post-therapy subspecialty care (17), demonstrating the importance of a patient's understanding of an insurance policy's "Terms and Conditions" outline. This same report (17) revealed a lack of knowledge regarding health insurance legislation relevant to this population such as the Americans with Disabilities Act (ADA), the Consolidated Omnibus Budget Reconciliation Act (COBRA), and the Family and Medical Leave Act (FMLA) among CCS, further highlighting the need for structured and intentional health insurance education.

In 2006, the Institute of Medicine report "*From cancer patient to cancer survivor: lost in transition*" identified the need for federal and state policy to ensure adequate and affordable health insurance for cancer survivors (18). The 2010 federal policy in the form of The Patient Protection and Affordable Care Act (ACA) increased access to insurance for young adults in several ways. (I) It required insurance agencies to cover patients with pre-existing conditions without additional costs (19). (II) It allowed patients to stay on their parents' insurance until age 26 (19). (III) In states that elected to take it, it expanded Medicaid (19), thus covering low-income young adults that might not otherwise have access to health insurance coverage. Despite instituting many protections that benefit CCS, data are lacking regarding the magnitude of and nature in which the ACA has changed care for cancer survivors (20). Studies have shown that CCS have relatively little knowledge about the benefits of the ACA, highlighting an area for needed education (20). Further, threatened repeal or replacement of these ACA provisions could create further confusion and uncertainty in an already complicated financial landscape (21). Thus, both advocacy for policies that protect and expand care for CCS as well as educational strategies to empower CCS to navigate evolving healthcare policies are vital for optimal care.

Organizations including "Livestrong, Stupid Cancer, and The Samfund & Triage Cancer" are increasing awareness of survivor-focused care and resources, including online educational information to help survivors navigate health insurance options (22-24). However, despite the growing number of online resources, there is a lack of peer-reviewed literature dedicated to clinic-based educational programs that support survivors' navigation of insurance coverage



**Figure 1** Model for delivering education on health care insurance—one model for providing longitudinal health insurance education is outlined here. This is a stepwise approach with age-appropriate educational topics listed in the order in which they are delivered. Topics may be repeated in each age block depending on the provider’s assessment of the patient’s comprehension of the topic. An important component of our program is the personalization of the discussions and information delivery, which is why the specific discussion topics by age are left intentionally broad.

options and subsequent healthcare experiences. Here, we aim to outline existing strategies that we have used within our comprehensive CCSP to provide longitudinal health insurance education and counseling to young adult CCS.

### Model for delivering health insurance education: experience of a large academic center

With the complexity of navigating the current health insurance environment paired with the importance of health insurance coverage for this population, there is a clear role for longitudinal education on health insurance for CCS in the clinic. The UMN CCSP has sought to incorporate this education into routine survivorship visits. The UMN CCSP, including patient demographics, the multidisciplinary team members, and program structure, has been described previously (25). To engage patients in health insurance education, the program uses a patient-centered, longitudinal model integrated into usual survivorship visits. The purpose of this education is to help patients understand the basics of health insurance, how to optimize their benefits, and how to eliminate lapses in coverage—all with the goal of protecting patients from long-term financial toxicity and preparing them to transition from pediatric to adult care.

In our multidisciplinary team, social workers provide targeted health insurance education as part of annual psychosocial assessments. These assessments occur in-person and include a series of questions asked by the social worker to gather information that provides a comprehensive evaluation of a patient’s overall well-being. It is critical that social work providers are familiar with insurance-related barriers to care, which relies on a familiarity with common insurers in a specific patient population and geographic region, the capacity to communicate effectively with insurers, and the ability to help survivors and families

navigate complex health insurance information. The capability to both support and empower CCS to manage their healthcare decision-making is also essential for this position.

The health insurance literacy program used at our institution was developed based on principles of Got Transition’s Six Core Elements of Health Care Transition ([gottransition.org](http://gottransition.org)), identifying insurance-related transition readiness milestones and timing from adolescence into adulthood. Milestones were adapted to CCS using the institution’s social work team consensus expert opinion. Education is provided in a developmentally appropriate, stepwise manner over several years, which begins during a patient’s visits in the pediatric CCS clinic and continue into their visits to the adult CCS clinic. *Figure 1* outlines our age-based model of developmentally targeted topics. The impact of cancer is variable—for each individual patient it has different effects on physical function, family and social relationships, cognition, and mental health. Thus, educational sessions are guided by the topics outlined in *Figure 1*, but these are intentionally an outline only rather than rigid objectives. This allows counseling and education to be individualized for each patient. At entry into care with the CCSP, an initial psychosocial assessment is performed by the CCSP social worker with questions related to a patient’s past, current, and future insurance coverage. The social worker gauges patient knowledge around health insurance, evaluates patient-specific needs, and provides individualized education and resources around future planning. This initial conversation helps to guide future conversations, and the social worker will choose topics and approaches to education that are tailored to the patient. Subsequent conversations happen during each patient’s yearly visit with a licensed social worker within a more extensive psychosocial assessment. Here we describe our

general approach to the content of these conversations.

Key aspects of health insurance literacy that are included in this CCSP program include: (I) how to verify that providers are in-network and tests are covered, (II) how to determine out-of-pocket costs, (III) available psychosocial benefits of coverage, (IV) what to do during a lapse in coverage, and (V) the role of financial counselors and how to contact them. Early conversations (patients age 10–12) are typically directed towards a patient's parents or caregivers. Once the CCS has reached early teenage years (ages 13–15), the provider will begin to direct conversations towards the patient themselves, which typically begin with an introduction of health insurance as a concept and progress to conversations regarding the importance of maintaining comprehensive health insurance into and during adulthood. Around the ages of 19–22, vocational planning becomes more prominent. Patients receive education on the importance of choosing a vocation that will provide adequate health insurance. If postsecondary education is within a patient's goals, they will be guided towards survivor-specific resources including survivorship scholarships. Provisioning these educational sessions into one-on-one visits between a patient and their CCSP social worker ensures that the material is provided to a patient in an individualized manner and that time may be allocated to specific aspects of navigating health insurance as dictated by the patient's needs.

Healthcare legislation, and the ACA in particular, has several implications for health insurance coverage for CCS, and thus is an important aspect to consider for education. Because of the ACA, many patients are now eligible for coverage under their parents' insurance plan until age 26, which has improved coverage during a vulnerable transition period. Thus, as CCS near that threshold of needing to obtain their own insurance coverage by age 23–25, insurance conversations revolve around the specifics of how to apply for health insurance. If these patients are purchasing insurance plans through the marketplace, it is important for them to pay attention to the specifics of these plans, as some may not authorize specialized survivorship care—in which case a plan must be made for transitioning survivorship care to the primary care setting. Regular communication during times of health insurance transition is aimed at minimizing lapses in coverage. While the provision of staying on parental insurance until age 26 is valuable, its impact is limited. It relies on parents having health insurance themselves, and for patients with parents who are employed in low-paying jobs without employer-

sponsored insurance, it is of little to no value. For patients over the age of 18 who need insurance due to limited parental income, estrangement from parents, or other circumstances, medical assistance (Minnesota's Medicaid) is introduced. This eligibility is possible in Minnesota because of expanded Medicaid through the ACA; in non-expansion states, Medicaid is typically offered only for a subset of young adults, and so these survivors can easily fall through the cracks. Thus, if this education is required, social work discusses the specifics of applying for this program and tax implications for parents.

## Conclusions

A model of promoting health insurance literacy for CCS by incorporating educational sessions into annual survivorship visits has been incorporated into the CCSP at our institution. Future work includes assessments of the efficacy of this program and perspectives of participating patients and families. Short-term outcomes will include acceptability and ongoing feasibility. Long-term outcomes of interest will be focused on efficacy such as the prevalence of financial toxicity due to inadequate or lack of health insurance coverage. Ongoing program evaluation is necessary to improve the quality and adapt the operational delivery of these educational messages in the changing landscape of care delivery that now includes telemedicine and will prioritize eliminating disparities. It has been our experience that educating CCS on the importance of maintaining health insurance coverage and the specific skills needed for navigating health insurance into adulthood is an essential part of survivorship care. We hope that our experiences may provide a framework for others who may wish to incorporate such a component into their model of survivor-focused care.

## *Recommendations and future opportunities*

### **Developing an educational strategy**

In developing an educational strategy, it is important to have knowledgeable educators capable of keeping up with the evolving landscape of insurance policies and able to effectively convey this information to CCS in pediatric and adult-centered care settings. Our program's current model is to provide insurance education in the setting of one-on-one social work appointments incorporated into the annual multidisciplinary survivor clinic visit. An alternative approach is to develop a group-based educational setting

that would also foster peer-to-peer connections for CCS. When the allotted time during the clinic visit does not permit completion of all necessary discussions, follow-up telephone calls may also occur. Within this institution's CCS teenage and young adult populations, we have observed that the health insurance literacy program is maximally efficient when incorporating insurance education into already-scheduled appointments as this provides convenience for CCS patients and maximal availability for this programming.

### **Collaborative learning and standardized workflow**

The development of best practice guidelines for delivering health insurance education to CCS is an area of unmet need. Creation of such guidelines would optimize the dissemination of these messages to survivors across the country. As health insurance literacy becomes a more prominent priority among CCSP nationally, there will be opportunities for collaborative research studies to evaluate discrete components of provided content and the modes of delivery that are most effective among recipients. Data from such a multicentered study will be crucial to the creation of broadly applicable best practice recommendations. Collaboration with multiple stakeholders from multiple disciplines will be critical to increase the reach and impact of future prospective research opportunities.

### **Timely policy updates and advocacy**

Several ACA provisions expanded healthcare access for CCS, notably expanded dependent care coverage through age 26 and removal of many limitations based on pre-existing medical conditions. In an ever-tumultuous political landscape, it is important to acknowledge that the future of provisions is uncertain, and it is imperative to include educational content updates as insurance legislation changes. Part of continuing education for professionals would thus include timely information on policy changes and their impact on the CCS population. Further, there is a need for providers to advocate for policies that protect and expand CCS healthcare coverage.

### **Vocational counseling**

As health insurance is still profoundly entwined with employment, vocational counseling remains critical for CCS. Care teams can guide CCS towards career pathways that are more likely to provide adequate insurance coverage by imploring patients to explore prospective employer's benefits packages and medical insurance programs

while making decisions about potential employment opportunities. Introduction to personalized vocational counseling should be age-appropriate and occur early in a survivor's career trajectory. Once survivors are older and already in the work force, topics include potential career or job changes and the related impact on health insurance (e.g., "job-lock"). This often includes referrals to community-based resources for career development and job counseling.

In conclusion, as our CCS transition into adult-centered care, being empowered with the knowledge to navigate health insurance is an integral part of having access to ongoing survivorship care. In our experience, longitudinal health insurance education can be integrated into routine cancer survivorship care. An ever-evolving political climate and uncertain future for the ACA have raised the need for ongoing and adaptable educational strategies. In the future, it will be critical to study insurance educational strategies to assess their impact and identify areas for improvement.

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