ASCO Annual Meeting 2026 Abstract

Conference Track: Pediatric Oncology – Survivorship

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Word Limit: 2,600 characters, including the abstract title, body, and table (not including spaces or author names or institutions).
Current Words: 2,599 characters

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Title: Perceptions of Medicaid Coverage and Care Experiences among Long-Term Survivors of Childhood Cancer: Qualitative Interviews from the Childhood Cancer Survivor Study (CCSS)

Background: Childhood cancer survivors require lifelong, risk-based follow-up care. Survivors insured by Medicaid may face barriers to coverage and care unique to this type of insurance. We identified barriers and facilitators related to coverage, access to quality primary and specialty care, and survivor-provider interactions among Medicaid-insured survivors.

Methods: Between May-November 2024, we conducted 23 in-depth interviews with adult survivors in CCSS currently also enrolled in Medicaid or with Medicaid coverage within the prior two years. Participants were recruited using stratified purposive sampling by state Medicaid expansion status, race/ethnicity, and age group. Interviews were audio-recorded, transcribed, and analyzed using thematic analysis.

Results: Participants lived in 10 states (6 expansion, 4 non-expansion), 52% rural. At interview, 91% were enrolled in Medicaid. Mean age was 39 years (median 39; range 28-55); 26% were Hispanic and 35% non-Hispanic Black. Cancer types included blood cancers (n=9), brain tumors (n=7), and other solid tumors (n=7).

When asked about maintaining coverage, survivors reported barriers including burdensome application/renewal requirements (e.g., in-person processes, extensive documentation); limited navigation guidance; and coverage instability tied to changes in disability status or income. Facilitators included assistance from knowledgeable staff (e.g., social worker), renewal reminder, and auto-renewal tied to Supplemental Security Income eligibility. Survivors expressed a need for hands-on help with application/renewal paperwork.

When asked about care access, survivors reported difficulty finding specialists and primary care providers (PCPs) who accept Medicaid and are equipped to address survivor-specific needs (e.g., implement recommended tests in survivorship care plans), appointment delays, and transportation/geographic barriers. Facilitators included long-term relationships with PCPs and effective PCP–specialist communication.

When asked about interactions with providers, survivors valued being heard, clear explanations, adequate visit time, and shared decision-making. However, many reported negative specialist encounters—feeling rushed or dismissed, including when new symptoms were repeatedly attributed to childhood cancer history without clear explanation, undermining trust.

Conclusion: Medicaid-insured survivors reported challenges in maintaining coverage and accessing primary and specialty care. Streamlining enrollment/renewal, strengthening navigation supports, and improving survivor-centered care within Medicaid are critically needed amid the evolving Medicaid policy landscape. Findings inform a larger study designed to quantify policy-relevant gaps in coverage among aging survivors.